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Military wives are supposed to be tough. They learn to “expect the unexpected.” Balancing a full-time job with four very active children while my husband was deployed to Viet Nam twice did help me to be strong. Yet when Joe’s diagnosis of cancer came in August 1979, it was like going to battle with an unknown opponent. This wasn’t something any of my family or friends had ever dealt with.

Life as we knew it was about to change! I had more questions than answers. This was a real challenge in 1979 when there was no internet.

If they removed his larynx, how would he communicate? Would he be disfigured? Would he still be able to remain in the Navy as a neck breather? Could he still coach our sons’ baseball teams? How long would it take to recover? How would it affect our friendships and family life? How could I balance my job, the children’s homework and all of their activities and still find time to be a caregiver?

I knew I couldn’t just sit back and have the answers fall in my lap so I decided to visit our local ACS office in search of information. That was the best decision I had ever made. They told me about a support group hosted at the ACS called the Tidewater Lost Chords Club. They offered to call one of the members and have them visit Joe at the hospital. That visit seemed to be the first day of the rest of Joe’s life.

Unfortunately, I wasn’t as successful finding ways for our children to cope and accept this traumatic change that was to take place. I felt like it was all on me to show them I was comfortable with what we were facing and that everything was going to be fine. I had gathered enough information to explain to the children what was going to happen. I allowed them to ask questions and get their feelings out in the open. Gina, our oldest daughter, drew pictures of what she thought her dad would look like after surgery with a feeding tube in his nose and clamps on his neck. They all had their own way of expression and by the time surgery took place, they seemed to be prepared. We were all determined to make the most of this.

Our oldest son Frank decided it would be a good idea for their dad to clap when he needed them. He could clap once for the oldest and four times for the youngest and so on. To say the least, they decided to have fun with this technique. Sometimes when Joe would clap twice for Gina, she would add another clap so her sister would have to go running. At that time, Joe was using a dry erase board to pass on messages. If Shelly (#3) was handed the erase board to bring to me, she might add something else onto his message like, Shelly has my permission to spend the night at her friend’s house this weekend.

A few weeks after surgery another person entered our lives. His name was Jim Leidman, a Speech Therapist. Because Joe was going through radiation and had undergone a right radical neck dissection, Jim decided the best option at that time was the Cooper Rand. (In 1979, there weren’t many options as it was before the TEP.)

Star Wars was very popular at that time and Joey, our youngest, thought his dad sounded as cool as R2D2. He would invite his friends over to listen to Joe talk like a robot. Our fear of them losing friends because their dad was different had diminished. We found out children are curious and this was a good way to teach them about the hazards of smoking and the consequences involved.

Life had changed for us but complacency can be boring. The fork in the road had led us down a path we never dreamed of; yet it led us to new and exciting experiences as well as new and exciting friends. We truly came to believe there is a reason for everything.

Maybe because we were young and had very busy lives, we didn’t really have the opportunity to think about being overwhelmed or distressed. Through my trying to help the children accept things, I was actually helping myself! Together we built our future.
ADVOCACY AND WHY IT IS IMPORTANT TO THE LARYNGECTOMEE

By Ann McKennis, RN (retired), CNOR(E), CORLN,(E)

There are many definitions of the word advocate. Basically an advocate is a person who publicly supports or recommends a particular cause or policy. This person is someone who pleads on someone else’s behalf. According to the National Safety Foundation, “An effective advocate is someone you trust, who is willing to act on your behalf and can also work well with the healthcare team.” To advocate means to inform and support. I have been an advocate for many laryngectomies over the last thirty years and it has been an honor and privilege. My primary goal has always been to teach the laryngectomy and his or her family or support person how to advocate for the laryngectomy after they leave the healthcare setting. This advocacy has become more important as hospital staff, especially nurses are stretched to the max trying to care for a large number of patients with varied conditions and have little time to spend at the bedside. After all, no one knows more about living with a laryngectomy than you do.

I want to teach you how to advocate for the laryngectomy and future healthcare experiences. If you are reading this as a longtime laryngectomy, you most likely have many stories of healthcare experiences that were frightening and perhaps life threatening. “They put an oxygen mask on my face, but I breathe through my neck.” Your medical and nursing staff may have NEVER seen a laryngectomy, not even in their training. Please consider this your chance to educate your healthcare provider. No one can do a better job.

Why is this important? First and foremost for your safety, you have a golden opportunity to educate those who care for you. According to the CDC, medical errors are the third leading cause of death in the United States claiming 250,000 lives. This is a frightening number and I want your healthcare providers to know you are a neck breather, and exactly what that means. Laryngectomy is not a common procedure. It is usually performed in a medical center and after recovery the patient returns to his or her home, often many miles away and in some instances another state. Your primary care provider, nurse, dentist, pharmacist, and respiratory therapist may never have seen a laryngectomy. The speech therapist in your area may also not be familiar with your surgery. This is your golden opportunity to teach and explain your airway. All of the vendors of laryngectomy supplies have great teaching handouts that are free. These are wonderful teaching aids that everyone can use. You are the expert! Use this knowledge to your advantage. You may ask “what can I teach these professionals?” Again, remember, you are the expert. For friends, family and your healthcare professionals in the community your airway and how you breathe is the most important lesson.

However if you are admitted to a hospital for illness or surgery, there are other things to consider. I would start with explaining your airway. How does it work? Explain that there is no connection from your mouth and nose to your lungs. The only way to get air or oxygen to your lungs is through your stoma. This is the number one priority! Ex-
Advocacy continued from page 5

plain to them the type of speech aid you use. They most likely have never seen an electrolarynx. If you have a tracheal esophageal puncture and use an in-dwelling prosthesis, explain what it is and the importance of it staying in place. Explain how you care for it. Let them know what you do for stoma care and how important humidity is to you. Air no longer goes through your nose where it would be moistened, but directly into your stoma; so the care of the stoma is very important. Speak to the dietician regarding your nutritional needs. Let him or her know if you have a feeding tube or cannot chew your food. Diets can vary widely so make sure they understand. Good nutrition is very important to healing. Tell the healthcare staff any special needs you might have. For example, talk to them about shower guards if you use them. Anything special and specific to your surgery should be explained. Ask to visit with the anesthesia providers preoperatively so you can make sure they are completely aware of your airway. Do not take for granted that they know! This also goes for the professional providing conscious sedation for colonoscopies and other outpatient procedures. It is much safer to assume they are not familiar with the laryngectomy airway. All these suggestions also apply to the primary caregiver. You are the advocate if the laryngectomee is unable at the time.

You can offer to visit nursing schools, hospital in-services or any venue where people meet for educational purposes. I participated in all these events taking laryngectomees with me. We even visited our senators and state representatives at the state capitol regarding issues pertaining to tobacco use, Medicare reimbursement and patient safety. The possibilities are endless.

Be aware that all hospitals have advocates if you run into problems. They are there for you. You have a right to competent care. If there is a problem, report it and use this as an opportunity to teach and advocate for all laryngectomees. I repeat you are the expert!

There are many areas in the community where you can advocate for the laryngectomee. Many volunteers are asked to talk about tobacco use and it’s dangers at schools and health fairs. This is a wonderful way to teach the public and the children love it. You might visit your local fire station and explain about your stoma and airway. Some first responders may think you have a tracheostomy. You are different because these patients still have a connection from their nose and mouth to their lungs. The laryngectomee does not.

PLAN TO ATTEND!

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While catching up on the morning WebWhispers postings this question prompted me to relate one of my favorite stories about “popcorn.” A local laryngectomee club of good size had a rather quiet president; with an enabling spouse that pretty much ran the show for him so he had no need to talk much. She felt she knew everything about laryngectomee rehabilitation because she had attended several conferences focused on laryngectomee issues. She set down the “rules to live by” for the club members. One of her dictums was “laryngectomees cannot, should NOT eat popcorn.” What? That was the silliest of her rules so far. The meetings usually included a pot luck lunch break. So… I decided on the spot that I would contribute the biggest bowl I owned filled with freshly popped popcorn...with lots of melted butter and salt. Yum! Smelled wonderful, even in the car as I drove the 50 miles to the meeting. She had a hissy fit over my endangering the members by offering this unsafe snack. Several members stood there with one handful of popped popcorn, indicating they could safely eat it... and safely swallow the well chewed stuff. Turns out her husband was long awaiting new dentures and still had no teeth. So, he said he couldn’t eat popcorn. That part of her understanding was true enough, but not suitable for a blanket statement for every one of us. Yes, popcorn can be safely eaten by most laryngectomees with some restrictions case by case that may change as necessary due to individual health issues.
The 2017 Delegates added Two New IAL Board Members

President: Tom Cleveland VP/Treasurer: Helen Grathwohl Secty: Barb Nitschneider Admin Manager: Susan Reeves

New: Dan Konz New: Kyd Dietrich (see below) Candy Moltz, MS, CCC-SLP Brian Mitchell, D.O.

Getting Back On The Job

By Kyd Dietrich

I was diagnosed with laryngeal cancer in August, 2012. As anyone that’s traveled that journey knows, you never forget the moment you’re given the horrific news and what will need to be done for you to have a chance at survival.

When I met with the multidisciplinary clinic, the lead physician said “we recommend that you have a total laryngectomy, followed with radiation therapy. We don’t think you’re a chemotherapy candidate.” Immediately dozens of thoughts began running through my mind. But there was one that was foremost and when the doctor asked, “Do you have any questions?” I said, “Yes, will this be career ending?” The doctor asked what it was I did and I explained to him that I was the Fire Chief in Hagerstown, Maryland. He said, yes, it would most likely be the end of my fire service career. That was devastating news for someone like me who loved what they did.

The next day I met with our City Administrator and Human Resources Manager and explained to them what was going to happen. I explained the different speech options that may be available after my surgery and the timeline of the upcoming procedures. At that point I asked our City Administrator if he wanted me to go ahead and file for retirement. It was at that moment that he did one of the most caring and compassionate things that anyone had ever done for me. He thought carefully for a few seconds and said, “No. Let’s see how things go, and if

Continued on page 11

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Continued on page 11
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you’re able to come back to work and you want to come back to work, the job is still yours.” Because my job was administrative and not hands on fire fighting, I was confident that I could still do my job and was motivated more than ever to get back to work.

I had my surgery on September 18, 2012. Three weeks later I had my first TEP installed and immediately I could speak without my electrolarynx. My radiation treatments began on November 1st and lasted until December 13th. During that time our City Administrator stopped by the house several times to see how I was doing, and to keep me informed on City business and things that involved the Fire Department. On December 18th he wanted me to make a presentation to our Mayor and Council concerning a staffing and funding issue, and that was my first experience of being back on the job. I’ll never forget the look of disbelief on some of their faces as I sat down at the conference table and occluding my stoma with my thumb, said “How do you like my new voice?” One of our Councilmen said, “Wow, I like it!”

By the beginning of January, 2013 my doctor had given me the OK to return to work on light duty. By the beginning of March, 2013 my doctor gave me the go ahead to return to full duty, which meant a forty to sixty-hour work week. I was elated! I was able to return to the job that I loved for over thirty years. Returning to work was a motivational therapy far better for me then any medication out there. I was fortunate enough to retire on June 30, 2015 for the reasons I chose, not because of some horrible disease.

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**Changing Seasons, Changes in Care**

*By IAL Medical Director, Brian Mitchell, DO*

This past summer in the northwest, we had an epic number of forest fires in the region, leading to very poor air quality. Seemingly, everyone complained of cough or a similar breathing complaint. Most affected were those who already had underlying issues such as adults with COPD or asthmatic kids, but surprisingly, I didn’t hear from many of our laryngectomees in the region. As I had seen people back since the summer, I asked how they avoided problems. Most have become accustomed to adjusting their self-stoma care to deal with changes in the seasons and weather. Winter always seem to be difficult with the furnaces coming on and drying out the air even further than usual. I’ve seen many creative ways of dealing with dry air and stomas but have always been on the lookout for more to pass along to my patients. Formal base plate type HMEs, “mud flap” type foam stoma covers, all manner of scarves and kerchiefs are common. Using saline bullets and coughing/suctioning along with tweezers for dry debris is often needed intermittently when the seasons change and particularly when the air quality is poor. Sometimes just going on a trip to a new area can stir up stoma issues. If you have some successful strategies to offer your fellow laryngectomees, reach out to an online support group such as WebWhispers or clue in your local SLP or ENT physician. You never know when your trick might be of benefit to someone else.
From the New Voice Institute Director

I am very honored to have been asked to serve as Voice Institute Director. I am eager and very excited about our upcoming meeting in Orlando, FL. I welcome all suggestions to help make this meeting the best! The VI is about training SLPs and others but ultimately it is about you!

Suggestions and questions can be sent to our new VI e-mail address, ialvoiceinstitute@gmail.com.

We now have a Facebook page!! The International Association of Laryngectomees Voice Institute. Check it out and ‘like’ and ‘share!’ Come back frequently as we will be posting often throughout the coming months leading up to the meeting in Orlando. The page will have information about faculty, the agenda and some fun facts and history about the IAL and VI that maybe you didn’t know! I’m looking eagerly forward to the Orlando meeting.

Sincerely,
Caryn Melvin, PhD, CCC-SLP
# IAL 2016 Financial Report

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<th>Revenues</th>
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<table>
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| Total Revenue in Excess of Expenses | $4,630 |

This report was taken directly off of the 2016 IRS Tax Return Summary
From the Voice Institute Director
Caryn Melvin, PhD, CCC–SLP

WHO SHOULD ATTEND THE VOICE INSTITUTE? There are a few answers to that question! The Voice Institute enrolls attendees according to 4 categories: VIPs, LTs, Health Professionals and Graduate Students.

VIP – VIP attendees are persons who have recently had surgery and are looking for assistance with communication, stoma care and who are seeking information regarding laryngectomy. Often VIPs are those persons with a laryngectomy who have not been able to connect with a speech pathologist in their area for care. Attending the Voice Institute will give VIPs the opportunity to meet with a speech pathologist and other professionals who can provide guidance and answer questions. VIPs will have the opportunity to receive instruction with their artificial larynx or standard esophageal speech. If they communicate with a tracheoesophageal voice prosthesis they can meet with staff to trouble shoot any difficulties or concerns and take suggestions and recommendations back home with them to their speech pathologist or health care professional. If a VIP does not have a speech pathologist the Voice Institute can likely recommend a speech pathologist in the VIP’s area who can help. The VIP can expect support, education, compassion and instruction throughout the Voice Institute.

LT- Laryngectomy Trainees are persons who have had their laryngectomy, recovered well from the surgery and are functional and successful with their method of communication. Laryngectomy Trainees want to learn more about laryngectomy and other methods of voice restoration so they can be of service to persons either pre-op or post-op laryngectomy surgery in their community. They are an invaluable support for new laryngectomees and their family members.

Health Professionals – Speech pathologists, dietitians, social workers, RNs and others who may be new to laryngectomy will find the information they seek at the Voice Institute. Instruction in all aspects of laryngectomy will be provided from assessment to management. Methods of communication will be taught and there will be many opportunities for hands-on exploration and practice. Health professionals will come away with a solid, holistic education in laryngectomy care.

Graduate Students – Graduate Students who attend the Voice Institute will receive an education not available in any graduate program. This is an excellent introduction to laryngectomy and affords the opportunity to participate in professional lectures, gain observation hours in voice, participate in therapy and many other hands-on opportunities. Students will work and learn side-by-side with LTs and VIPs as well as the Health Professionals who attend. This is a unique learning experience for students and an opportunity to hear not only from professionals working with laryngectomees but also from the individuals with a laryngectomy and their families.

Looking forward to a great meeting in 2018!

Editor’s Note: In the August 2017 issue of the IAL News, an error was noted on page 10. Lauder Enterprises was inadvertently omitted from the list of supporting vendors of the Newport News Annual Meeting and Voice Institute. Apologies have been extended to Jim Lauder. We thank Lauder Enterprises for their support.
It was October, 2006 when I was speaking to an auditorium full of parents and children. As I started to speak, I could not get my words to be heard. I went to a doctor and I was told that I had throat cancer. I started Radiation & Chemo immediately (40 Radiation treatments + 8 Chemo sessions). Afterwards, my voice was still not clear so I went to Bastian Voice Institute (BVI). They viewed my x-rays and they told me that I needed a complete laryngectomy ASAP as the cancer was about to spread.

In March of 2007, I had a full laryngectomy and my voice box was removed. That was the start of a very trying period of time in my life’s journey. Three weeks later, I had an indwelling prosthesis inserted that enabled me to speak with some difficulty at first. Now I am a very awesome speaker!

Since owning my own business and working from home, I was able to keep working with the help of my wife, Rosemary. I am very active and exercise at least five times a week. Being a “Lary” has not slowed me down at all!

In 2008, my Doctors at BVI asked me if I would start a Support Group in their office for other “Larys” and their families. That was about 9 years ago and it is still going strong. Our “Talk Again” group meetings are all positive and our speakers are all positive. We have made such an improvement in the lives of our support group, caregivers, family and friends. I love this group and I know that I have made a difference in people’s lives.

I currently speak at colleges (for SLP’S), high school career days, chamber events, etc., to let everyone know that being a laryngectomee is not a death sentence. It lets them know that their life is so valuable and it helps others to know how to survive in the face of adversity and still be a positive influence in peoples lives.

Being a competitor and a very positive person, I decided that I would be a Warrior and not a Victim. To succeed, you must never ever give up! The choice is totally yours!

God was by my side the whole time (He always is) as I went through this blip in the road. I knew that God had a plan for me and then it was clear what my plan was: to help other “Larys”!

God Bless you on your journey as a Laryngectomee!

By: Dan Konz
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Thomas Cleveland  
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Planning Ahead

Would your club be interested in hosting the IAL Annual Meeting during the summers of 2019 or 2020? Please submit your application to the IAL Board of Directors! The IAL has been east more than west in the last few years. Can YOUR club help bring the IAL to your neck of the woods? There are complete directions on the IAL website at www.theial.com. Thank you.

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