The International Association of Laryngectomees
Vol. 71 No. 1, February 2022

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* Orange Emergency Cards
* 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

Table of Contents

Our Valued Advertisers
InHealth HME, hands free valve………………………2
Atos, Provox Life
Speak Free HME ……….20

Contents
My Story of Having Cancer Twice………………………4
President’s Message...............6
Living the Lary Life.............7
Choosing to Go Big………………10
Caring for Airways and Neck in Cold Weather………………11
Lung Cancer…………………12
Treatment for Laryngeal Chondrosarcoma………………14
Make your hotel reservations 15
AM/VI Registrations ….16 &17
Voice Institute Updates……… 18
In Loving Memory………………19

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

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!
My story of being hit twice with throat cancer.
By Tom Cleveland

To my best recollection I started smoking in 1965 at the age of 13. I started with unfiltered cigarettes and then went to Menthol.

In or around 1993 I was having issues with my voice.

I was a very good singer in school and in church. I was blessed with a very good range of voice. I sang in choir and in glee clubs and sang in a quartet and duo. I loved nothing more than to sing.

I started driving a truck in 1970 with my Dad who was a mail contractor for the U.S. Postal Service. This was only part time until I married my first wife in 1975 and then started driving full time.

It was a good job but physically demanding. I was required to load and unload the mail bags which could weigh in excess of 90 lbs. By now I was up to smoking about 3 packs a day.

I divorced in 1979 and had 2 boys to take care of.

I met my present wife Valerie, at the Kalamazoo Post Office in June of 1980 and was married in September of that same year. We have 2 girls.

I was having some trouble talking and singing and decided I should go see the doctor. My family doctor sent me to an otolaryngologist right away. He took one look into my throat and sent me for a biopsy and said I had stage 3 laryngeal cancer and needed a laryngectomy.

My wife and I decided it was necessary and in April 1995 at the age of only 42, I had the surgery that took away my voice as I knew it. It was a bit upsetting once I really realized I could not talk. The doctor never told me or my wife what to expect and we never saw or knew an SLP. I really did not want to meet old people that had a laryngectomy. I never knew anything about this surgery and how it would affect me and my family. My 2 daughters who were 12 and 10 at the time were very scared and afraid their Daddy would die.

My Pastor at the time, said I should make a voice recording before I have the surgery for them to listen to. I did a recording to each one of the family. It was the best thing I ever did. Until we could figure out what to do, the family had to pay attention when I needed something. I would either clap my hands or stomp my foot on the floor and they would come running and see what I needed. I had no way to communicate with anyone except to use a writing pad. After I got some voice communication back the hand clapping and foot stomping went away. I would try it from time to time and by then the kids would say “what” instead of coming and seeing what I needed. This became like a game to them and we could all get a good laugh.

This was very hard on the family, and I think harder on them than me. I knew I could not talk and I was hard to communicate with, but I could tell how it was affecting them.

It was 6 months before I had any idea how to talk. My sister-in-law told my wife to contact an SLP at Western Michigan University by the name of Dr. Erickson. This man gave me an electrolarynx (EL) and showed me how to use it and for the first time in 6 months I said my first words. (What do you want me to say?). I started going to schools and talking to the students about smoking. They were really interested and couldn’t believe how I was able to talk.

I met a wonderful man, Orin (Pat) Armintrout, who was having a hard time learning how to
speak and I was asked by Dr. Erickson to come in and help. I was still using my EL, but Pat opened my eyes to a voice prosthesis, which is what he was using. I had the puncture done and was talking and even singing with the prosthesis. It was great and I continued to talk to students with my new voice.

After a short while I contacted ACS to see if I could go talk to students in schools about smoking. I met a wonderful young lady (Maureen DeCorte) who helped me do what I needed to do. She got me into some schools and the more I talked the more schools asked me to come to their school.

I started to have a problem with my speech again and had stopped using my voice prosthesis because it was too hard to talk with it. I quit my school presentations because of this and started using my EL again. This was hard on me as I did not like to have to go back to the EL.

In early 2019 I was sleeping a lot and my throat was getting very sore and my neck was turning red and swelling. I was in a lot of pain, and it was very hard to swallow. I finally went to an otolaryngology doctor for a look. She looked and said it was just an infection. My wife and I thought not but I went home and continued my sleeping about 20 to 23 hours a day. I returned to my local SLP doctor again and this time she pushed on my neck area where it was swollen, and I about jumped out of the chair because of the pain she inflicted by doing this. Again, she said she did not know what was going on. I asked her to scope me, but she refused. We went back home I told my wife I was going to email Teresa Lyden my SLP at University of Michigan (U of M)

I emailed Teresa Lyden and attached a picture of my throat area and the next day I got a reply with an appointment to see Doctor Spector that November. This was a “PRAISE the LORD” moment as I say, because Teresa said she rarely looks at her email but just felt that day she had to and there she saw my email. We got to U of M, and he took one look at me and said we need a biopsy. The biopsy was done, and we were told that I have neck cancer once again. I was not surprised by the diagnosis but was a little scared of how far it had spread.

My surgery was scheduled for January 16, 2020. I asked that my voice Prosthesis be removed and not put back in. Doctor Spector finally said yes and removed it. I am glad I had decided to have it removed because now I can swallow again. I had to have a flap done and Doctor Spector said he would take some muscle from one of my legs to make the flap. The blessing of my first cancer was that it had helped contain the spread of my second throat cancer. I am so thankful that my Jesus held my hand through all of this. From my wife Valerie to the Doctors and Nurses, to PT, Jesus was there. I had no radiation or Chemo afterwards. The pain of this surgery was like nothing I ever had before. My first surgery was nothing compared to this one. I would wake up with such a burning like sensation in my neck I would just shake. All this time my wife Valerie never left my side. She slept in the room recliner as much as she could when I was not waking her up for help.

I was not a good person with the hospital staff. I was very rude and at times mean. I would not let them touch my lary tube at all. I would remove the tube if they wanted that. I am not
sure why I was so rude to them, but they
treated me very good even though I was not
nice. The staff really had no idea how to care
for me since I had already had a
laryngectomee and knew a lot of what I could
and could not do.

I had one of my daughters bring up my EL so I
could talk. The first time I used it the nurses
looked at me strangely as they had never
heard or seen one of these. Doctor Spector
said no one after this kind of surgery was given
one because they put in the voice prosthesis.
They showed my wife Valerie, how to care for
my throat and leg when we got home. I had
some PT while I was in there but I did not need
very much. The 2-foot-long scar on my right
leg from my hip to my knee had very little pain
but needed Vaseline on it 2 or 3 times a day so
it would not get dry. After we finally were
allowed to go home, Valerie continued to take
care of me as I healed, as she always has, in
the 41 years we’ve been married.

We now have 12 grandchildren and 3 great
grandchildren. What a blessing it is to be alive
at the age of only 69 and beaten cancer twice.
You never know what is coming down the road,
and without knowing Jesus as my savior I am
not sure I would still be here to tell my story.

******************************

Life is a journey
In which most of
Us get travel sickness

President’s Message

I am hoping and praying that we all have a
happy, healthy 2022. I am looking forward to June
and our Annual Meeting/Voice institute. If you have
never attended one, please try to make this one. You
will not be sorry and I can assure you that you will
go home with a whole new outlook on your life. Just
being in the majority of people like yourself, can
really make a difference. There is no one to criticize,
only to help, when you have a problem with your
speech. Some of the best esophageal, EL and TEP
speakers will be there and are willing and able to
assist you in attaining a good voice. There will be
some of the top medical professionals there to teach
and assist you in any way they can.

If you have never been to an AM/VI, plan to attend
all of the Voice Institute classes. They will begin on
Wednesday morning, June 15 at 9 am. These are the
same classes the SLP’s will attend and they are open
to all laryngectomees. You can come away with a
world of information and a better understanding of
your anatomy, knowledge of how you are able to
speak and how to solve some problems you may
encounter or have already encountered. You are free
to ask questions and hopefully you will learn all that
you can. We are providing a $20 discount on the
registration fee for all first time attendees.

There has been some concern voiced about Covid
and I want you to know that we will abide by the
North Carolina state guidelines and do everything
we can to keep our attendees safe and Covid free. If
you are not fully vaccinated, please be ready to wear
a mask at all times in consideration of others.

We are also planning to have a showing of “Can You
Hear My Voice.” This is the movie about the
laryngectomee choir in England. The producer of the
film, Bill Brummel will also be on hand to talk with
us. I know that none of you wants to miss out on the
fun. By the time you receive this newsletter we will
have the AM/VI registration on our website:
theial.com and there will also be a link for the hotel
reservations. Looking forward to seeing as many of
you that can possibly attend.

Regards, Helen
Living the Lary Life
Mackayla LaPlante

It’s so funny and dreadful how much we take for granted in our daily lives. And scary just how fast we can lose the things we take for granted. Some people lose their limbs, some people have a stroke and lose their motor skills, some people go blind, some people even lose their voice. There are many other things people lose all the time that greatly affects the way they live.

I lost my voice. I was 20 years old. It was during a time that was supposed to be the beginning of the best part of my life. I was pregnant with my first child. A perfect healthy baby girl. My pregnancy was hard despite her being so perfectly healthy. The challenges I was facing were making it difficult to live. I say that quite literally. I couldn’t breathe well and if you can’t breathe that jeopardizes your life and in this case, the life of the child growing inside of me.

It began in April of 2020. Ironically just about the time the COVID-19 pandemic began. The daycare I worked at had to shut down. During the time of the shut down, I contracted pneumonia. I got over it pretty quickly with some antibiotics. After I was better I noticed my voice was raspy. My mom was constantly telling me to clear my throat. It never worked. Over the next few months it got worse and I’d lose my voice quite often. I thought I’d messed up my vocal cords from being sick and coughing so hard. I was wrong about what was affecting my vocal cords, but I was right about it being my vocal cords.

In August of 2020 I found out I was pregnant. I had my first ultrasound. Her dad and I were so excited and we thought NOTHING could ruin this beautiful journey. We were so wrong. It was still a beautiful journey, but an incredibly difficult one that I wouldn’t wish on my enemies.

“It’s just asthma!” the doctor said as she wrote me a script for an inhaler. Despite me telling her the wheezing was in my throat. I got worse.

“Maybe it’s your heart!” said another doctor. She sent me to the cardiologist. I do have a rare heart condition it turns out, but it’s unrelated to my breathing. Considering I also told her I felt like it was my throat.

“Maybe you have blood clots in your lungs!” said the emergency room doctor. “It’s a common pregnancy issue.” he added. Nope. No blood clots in my lungs.

“Your baby is just pushing on your lungs and making you think you can’t breathe. It’s really all in your head.” said the high risk doctor I traveled two and a half hours to see. He never even did an examination. He never listened to my heart or my lungs. He did nothing.

By this point, it felt like something was constantly gagging me. I’d cough and cough and cough. It never stopped. The mask mandate made it so bad. My breathing was already so compromised and adding a mask to it? Yikes. I was waiting for the day I would pass out in the middle of Walmart. I never did but I’m sure everyone thought I had COVID-19 the way I was coughing and gasping for air.

I was sent to a new doctor. The morning of my appointment I noticed I had an “Adam’s Apple”. That was odd. Now I knew it was my throat. How could it not be? I did some googling and figured out the wheezing from your throat is called a strider. I did some more digging and came to the conclusion (because I’m clearly a doctor! Not.) that it was my thyroid. I was told early on in my pregnancy that they wanted to put me on thyroid medication after I had the baby. So in my head it all added up. Most people probably would have thought the same.

Anyway, this new doctor sent me to an ENT. Finally! Someone who specializes in this! I was so excited to finally figure out what was wrong with me. I figured worse case it was thyroid cancer and I’d have it out and do some treatments and move on with my life.
The day of the ENT appointment arrived. My fiancé dropped me off. I told him it should only be an hour or so. I got into the office and she did a scope down my nose and immediately sent me to emergency room. Great I’m probably dying.

I got to the emergency room and they told me that I needed an emergency tracheostomy and that they were going to life flight me to the hospital two and a half hours away because they were more equipped to deal with a NICU baby in case she went into distress during the procedure. Can someone say ANXIETY! And of course COVID-19! So I had to do this all alone. I was more worried about my baby at this point though.

They got me loaded into the plane and I got to the hospital. All I really remember is so many people crowding around me and then this crazy doctor tried to slice my throat open while I was awake. So I obviously started screaming at her and tried to get my arms out of the restraints. They sedated me.

The ICU was lonely. All I could hear was old people yelling for help because they couldn’t figure out how to call the nurse. There was a tube stitched into my throat. My baby was still inside of me though. Still growing. Still healthy. Still trying to break my ribs. That made things a little less lonely. To make everything worse, my fiancé’s father died. Being in the hospital during this time was really hard. Neither of us could really be there for the other 100 percent.

The trach tube was miserable. I couldn’t talk. I have communication issues when I can talk and not being able to talk just made me not want to communicate with anyone at all. Writing things down was extremely exhausting and eventually I found an app called text to speech that would talk for me. It was still annoying and frustrating. They finally sent me home after a second biopsy and getting me all set up with supplies and making sure I could take care of myself.

The first shower I took was awful. I was scared I was going to drown myself. So my mom helped me wash my hair. It took a few times before we figured out how to get water down my trach. I took a break from washing my hair in the shower for a week and only washed my hair in the sink. I eventually got over my fear and was able to shower almost normally. I just couldn’t face the water.

A week after I got home, I received the most disgusting phone call I’d ever received in my entire life. To this day her voice still pops into my head. She’s a nice lady. A good surgeon. And I know it wasn’t her fault she had to tell me I had laryngeal cancer over the phone. But it made me hate her. The next few weeks I spent in my bed, in the dark. Until I started coughing up blood the week before I was due to have my cesarean section. So of course I ended up being brought to Bangor in an ambulance and was admitted again. My trach was rubbing against my throat causing a never ending scab to form. I’m not sure where this falls in the timeline but for one of my follow ups, I coughed blood all over her windshield. It looked like a murder scene.

Finally, a good day. The day Avery was born. April 8, 2021. The BEST day of my entire life. She was so perfect. I didn’t think anything could ruin it. Until I got a MASSIVE mucus plug that plugged my trach tube and cut off all of my oxygen. I could breathe in but it would plug again so I couldn’t breathe out. I’d just been sliced open and glued shut and now I’m about to pass out from lack of oxygen. I don’t mean to cuss, but I quite literally scared the shit out of all the nurses on the Nursery floor. Thankfully one of them knew a little bit about trachs. In the process of me trying to rip my trach out she found some saline bullets. If you know what these are then you know how magical they are. If you don’t know, it’s a capsule filled with sterile saline solution that you can put down your trach or stoma to break up mucus plugs. Basically life savers. Also, let me just say, OW! I could have swore I pulled my incision apart and felt like my guts were about to fall out all over the floor. What a day.

Fast forward a little bit. I finally went home and had my PET scan. Stage 4 with possible lymph node involvement. Meaning chemo and radiation probably weren’t gonna save me. And if they did I’d probably have the trach forever along with a permanent feeding tube due to possible aspiration problems because my vocal cords were as good as paralyzed. Dana Farber in Boston, Massachusetts agreed. Let me just add that my surgeon was completely rude and apathetic and treated me poorly because I didn’t want my vocal cords removed.

5 weeks postpartum. I wasn’t even healed from having my baby. And I had to leave her. I had to leave her to go have my neck mutilated. They took my voice box, my thyroid, and 92 lymph nodes. And to bring up another reason I dislike my surgeon, she
never once mentioned thyroid removal could be a possibility and she NEVER got permission to remove it. I didn’t even know it was gone until 3 days later when I asked what my meds were for. Now obviously I would have said go ahead or my mom would have if it needed to come out, but we were never asked or told and I feel like that was wrong. She also removed 92 lymph nodes when only one popped up as possibly affected. I now have to take a thyroid hormone supplement for the rest of my life and I have severe lymphedema in my face, neck, and chin. It’s painful. And none of my lymph nodes were even cancerous. My chin feels like a balloon that is ready to pop any second.

I was in the hospital for two weeks. I wish I had more details for you but I just remember wanting to kill myself and doing puzzles with my mom. And a really special nurse who drilled it into my head that I was “Tough as nails.” Oh I can’t forget the feeding tube. I thought getting the mucus plug in my trach after the c-Section was bad. This was worse. It felt like all of my ribs were broken even after reaching the highest dose of fentanyl they were legally allowed to give me. Which didn’t take my pain away and almost put me into respiratory distress. I do not recommend. The last two things I really remember were the first time I looked at my stoma and the first time they made me talk with the electro larynx. I won’t lie, I wanted to light the surgeon on fire for mutilating me like this.

I’m six months post operation, seven months postpartum, and three months post radiation. Radiation was terrible. I lost every taste bud in my mouth and my neck was crispy and it drained me. It’s still draining me. I’m still trying to cope with everything. It took me a while to use my TEP to talk. Everyone says I sound good for not having vocal cords but to me it sounds like nails on a chalkboard. I suppose I’ll get used to it eventually. Anything is better than that awful electro larynx. I’d rather be mute. And I was until I worked up the nerve to get over my disgust of how my TEP voice sounds. I’m still trying to wrap my head around having a hole in my neck for the rest of my life. But I’ll get there. I’ll be okay. And so will you.

“Believe”

Life is so short.

We spend so much time sweating the small stuff; worrying, complaining, gossiping, comparing, wishing, wanting and waiting for something bigger and better instead of focusing on all the simple blessings that surround us everyday. Life is so fragile and all it takes is a single moment to change everything you take for granted. Focus on what’s important and be grateful! You are Blessed! Believe it! Live your life and leave no regrets.

Mirror Mirror on the Wall,
I’ll always get up after I fall.
And whether I run, walk or have to Crawl
I’ll set my goals and Achieve them all.
Choosing to Go Big
Stacey Brill M.S.CCC-SLP

One can do their job, and do it well, or one can decide to go beyond the job description and try to change the world. Your change can start small, and stay that way while still making a difference, or you can try to go big. This is my journey of going beyond my job description to make a difference. It is also my story of going big.

As a Speech Language Pathologist who specializes in working with head/neck cancer patients, I had spent many years listening to my patients discuss the limitations of their insurance plans. It was disturbing how many services were not covered, no matter how good the insurance. My heart told me I had to do something more to help not only my patients but all head/neck cancer patients in my community. My official job is as a therapist, but I have always felt my role should be as an advocate and a voice when nobody else would listen. I decided MY change would be to help patients afford services insurance didn’t cover. The question was how?

After considering various options, ten years ago I approached a small but national Oncology Foundation and pitched my idea of hosting a 5k run and 2 mile walk to raise awareness and funds for local head/neck cancer patients in Southwest Florida. They agreed to assist me in my goal and a change movement was born. What started, that first year, as a small local event, has blossomed into a yearly well attended tradition. April 2022 will be the 10th anniversary with over $250,000 raised, all of which has stayed in the immediate community to help patients in need.

I wanted my change to meet the needs of all patients. Thus, the financial assistance program created is unique in that anyone with a head/neck cancer diagnosis can apply. Differing from other programs, financial assistance is not based solely on income. Recipients can have a job, own a home, and have health insurance. The program was designed specifically to deal with what I was witnessing, including patients with health insurance going without services and supplies because there were high copays or supplies were not within their budgets. Consequently, with the financial assistance program, any patient, regardless of income, who applies and is approved has been given funds. These funds have covered PT/OT/Speech Therapy co-pays; dental assistance for dentures, extractions, and obturators; feeding tube supplies/formula; laryngectomy supplies; nutritional supplements such as Ensure; compression garments for lymphedema; Trismus devices and other needs related to their diagnosis.

Now the “Go Big” part... It has always been my dream and vision to expand my change to a national movement to raise awareness and funds for head/neck cancer. I’m excited and proud to say that 2022, I will see my dream come true. In April 2022, 5k runs/2-mile walks will be hosted in Cape Coral, FL; Broward County, FL; Asheville, NC; and the Tri-City area in WA state. The current plan is to add five new locations each year starting in 2023. Funds raised at each venue will stay locally to provide financial assistance for patients in those areas. Thus, the small but ever-growing change in my community will now be a change in multiple communities around the country.

If you would like to join the movement, please check out our website www.yourpartnersincare.org. You can register there to walk or run at one of our race locations or to participate virtually. We are also always looking for volunteers for race day. If you know anyone interested in volunteering, please contact us on the website ... for students, we are set up to school volunteer hours. Donations can also be made on the website. There are many ways you can get involved; just reach out to us at info@yourpartnersincare.org. We would love to hear from you and let you know how you can get involved and, in 2023, perhaps host your own run/walk event.

Going big has finally started! 2022 is going to be a great year and, with this expansion, I am excited to have begun my national change movement. More importantly, I am thrilled that the movement will change the world for other therapists and supporters as they help their patients in need across the country.

Life is short. Cut out the negativity. forget gossip, say goodbye to people who hurt you. Spend your days with people who are always there.
Caring for the airways and neck in cold weather

Winter and cold weather can be rough for laryngectomees. Before laryngectomy, air is inhaled through the nose where it becomes warm and moist before entering the lungs. After laryngectomy, the air is no longer inhaled through the nose and enters the trachea directly through the stoma. Cold air contains less humidity than warm air and more irritating to the trachea. This result in drying of the trachea, increased coughing, mucus production, irritation and inflammation of the airway. This may increase the risk of infection, blood-tinged mucus and crusting in and around the stoma. The mucus can also become dry and plug the airway.

Breathing cold air can also have an irritating effect on the airways causing the smooth muscle that surrounds the airways to contract (bronchospasm). This decreases the size of the airways and makes it hard to get the air in and out of the lungs causing shortness of breath. In very cold weather, the moisture in the HME can freeze making it even harder to breathe. When this occurs, replacing the HME can bring some relief.

Caring for the airways includes these steps described:

- Avoid exposure to cold, dry or dusty air
- Avoid dust, irritants and allergens
- When exposed to cold air, consider covering the stoma with a jacket (by zipping it all the way) or a loose scarf or bandana and breathing into the space between the jacket and the body to warm the inhaled air. Another option is to wear a scarf or a thin T-shirt over the face; that cover the nose, mouth, and stoma; like a mask. This will keep the neck and face warm and create a space for the exhaled and inhaled air to warm up and stay humid. It also allows for air filtration and oxygen and bicarbonate exchange with the environment.
- Temporary removing the HME under a cover (see above) can be helpful allowing greater air exchange
- Use an HME which enables greater airflow (i.e., Provox XtraFlow HME, Provox Life - Go HME, Provox FreeHands HME Flow, Blom-Singer EasyFlow HME

- Replace a frozen HME with a new one
- Keep the airway humid by wearing an HME and inserting saline bullets
- Cough out or suctioning the mucus using a suction machine to clean the airways

Following a laryngectomy which involves neck dissection most individuals develop areas of numbness in their neck, chin and behind the ears. Consequently, they cannot sense cold air and can develop frostbite at these sites. It is therefore important to cover these areas with a scarf or garment.

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/
Lung Cancer

LUNG CANCER IS THE LEADING CAUSE of cancer death among men and women. Tobacco is the biggest risk factor for lung cancer, but approximately 20% of people who receive a diagnosis have never smoked or used any other form of tobacco.

Many new therapies, including targeted drugs and immunotherapies, have been approved in recent years to treat lung cancer, improving outcomes for many with the disease.

WHAT IS LUNG CANCER?
Lung cancer occurs when cells inside the lungs grow out of control.

The cancer can start in the bronchi, the tubes that allow air to move from the trachea into the lungs; bronchioles, the tiny tubes that carry air farther inside the lungs; or alveoli, the air sacs within the lungs.

There are two types of lung cancer: non-small cell and small cell.

- Non-small cell lung cancer, by far the most common type, is divided into three subtypes:
  - Adenocarcinoma starts in the cells that secrete substances such as mucus. Although it occurs mainly in people who have smoked, it’s also the most common kind of lung cancer in people who never smoked. It is found in the outer part of the lungs and most likely to be discovered before it has spread.
  - Squamous cell carcinoma occurs in the center of the lungs in cells that line the inside of the airway and is often linked with a history of smoking.
  - Large cell, or undifferentiated, lung cancer can appear anywhere in the lungs and tends to grow and spread aggressively.


WHAT ARE THE RISK FACTORS?
Smoking is the leading risk factor for lung cancer. Others include secondhand smoke; exposure to radon, asbestos or workplace chemicals; radiation therapy to the lungs; air pollution; and a personal or family history of lung cancer.

WHAT ARE THE SYMPTOMS?
Lung cancer often causes no symptoms until it has grown past the early stage. Symptoms can include a persistent, worsening cough that may bring up blood; chest pain, especially with deep breathing or laughing; hoarseness; loss of appetite; shortness of breath; fatigue; wheezing; and bronchitis or pneumonia.

Lung cancer that spreads to other parts of the body can cause bone pain, such as in the back or hips; nervous system changes such as headache, dizziness or seizures; yellowed skin or eyes; or swollen lymph nodes.

HOW IS LUNG CANCER DIAGNOSED AND STAGED?
Most lung cancers are found because a patient has symptoms, although some are detected through screening. Health insurers will cover periodic screening via low-dose CT scan for people with a history of heavy smoking. Screening can reveal lung cancers when they are still too small to cause symptoms and are more likely to be curable. If lung cancer is caught before it spreads, the likelihood of surviving five years increases to 60%.

Although only low-dose CT scans are recommended to screen for lung cancer, doctors who suspect lung cancer can use a chest X-ray, MRI, positron emission tomography scan or bone scan, which uses radioactive material to pinpoint abnormal areas.

If any of those points to lung cancer, pathologists can look at the cells to determine whether they are cancerous. The cells can be from mucus coughed up from the lungs, fluid removed from the area around the lungs, or a needle or surgical biopsy of lung tissue.

If cancer is present, determining whether it has spread past the lungs can be revealed through additional tests: ultrasound of the lymph nodes; mediastinoscopy or mediastinotomy, which checks between the lungs; and thoracoscopy, which checks the spaces between the lungs and chest wall.

Patients with lung cancer should request that their treating physician conduct comprehensive biomarker, or genomic, testing of their tumor tissue, which can help determine which treatments are likely to be most effective. Genomic testing looks for altered genes that drive cancer and can be treated with targeted therapies. There are approved targeted therapies for alterations in these genes: EGFR, ALK, ROS1, RET, NTRK, MET and BRAF. Testing may also look for gene alterations that do not have approved therapies but have drugs being tested in clinical trials. Comprehensive biomarker testing includes looking at levels of certain proteins called PD-1 and PD-L1, which may influence whether a patient should receive immunotherapy.
Non-small cell lung cancer is divided into stages from 0, the least advanced, through 4, the most advanced. Small cell lung cancer is divided into two stages: limited and extensive.

HOW IS LUNG CANCER TREATED?

Non-Small Cell Lung Cancer

For early-stage disease, surgically removing part of the lung may be the only treatment needed. Surgery may be followed by chemotherapy and/or radiation.

Treatment for stage 2 non-small cell lung cancer entails surgical removal of part or all of the affected lung and any cancerous lymph nodes followed by chemotherapy to kill any remaining cancer.

The mainstays of stage 3 treatment are chemotherapy and radiation given together, sometimes followed by surgery if the cancer can be removed, and then more chemotherapy and radiation. If the cancer has grown too much to be completely removed by surgery, chemotherapy and radiation alone may control or even cure it. These treatments may be followed by immunotherapy to help keep the disease stable.

Stage 4 non-small cell lung cancer has spread extensively and is difficult to cure. The goal of treatment is to prolong life and increase physical comfort. Therapies are selected based on the number of tumors and their location. The same treatments used in earlier stages, plus targeted therapies and immunotherapies, can be considered depending on the results of tests on the tumor cells. Some of these newer biological therapies can extend lives.

Small Cell Lung Cancer

Chemotherapy and radiation therapy to the chest are typical treatments; sometimes surgery is performed first, but it is not possible in many cases.

Radiation therapy to the head may be used to help prevent the cancer’s spread to the brain.

If the cancer is extensive, chemotherapy plus immunotherapy is usually the first treatment. This may be followed with radiation to the chest and brain.

Clinical trials of new treatments can be considered for either limited or extensive small cell lung cancers, which may shrink significantly with standard therapy but have a high likelihood of recurring.

WHAT ARE THE POTENTIAL SIDE EFFECTS OF TREATMENT?

Side effects of surgery can include pain, cough, fatigue and difficulty breathing. Chemotherapy can cause low blood counts that can lead to infection, nausea, diarrhea, hair loss, fatigue, mouth sores and numbness or tingling in the extremities. Those who receive radiation may experience mild skin reactions, nausea, fatigue or sore throat.

Targeted drugs can cause high blood pressure, bleeding, headaches, mouth sores, diarrhea, skin problems, constipation, vision changes and dizziness. Immunotherapy can cause fatigue, nausea, cough, itching, joint pain, constipation and diarrhea. A palliative care specialist can help patients with lung cancer manage side effects at all stages.

HOW DOES LUNG CANCER AFFECT A PATIENT’S LIFE?

Lung cancer stigma can affect patients who are seeking support. Symptoms from the disease or side effects that arise from treatment can affect quality of life, so patients should talk with their providers about the importance of emotional and physical support during this time.

WHERE IS HELP AVAILABLE?

The American Lung Association (lung.org/lung-cancer, 800-586-4872) offers information about lung cancer, online support communities, initiatives to raise awareness and funding, and more. Visit lung.org/lung-cancer to learn more. And don’t forget to visit CURE’s resources guide at curetoday.com/journey to learn about additional help that is available.
New Surgical Procedure to Treat Laryngeal Chondrosarcoma

Laryngeal chondrosarcoma is a rare type of cancer that grows in the cartilage tissue that makes up the larynx, also known as the voice box. Traditionally, treatment options have been both limited and bleak. The current standard of care is a life-changing surgery that removes the larynx entirely—forever changing the way a patient speaks, breathes, and swallows.

Experts at the Grabscheid Voice and Swallowing Center of Mount Sinai and Head and Neck Institute are leading the way in advancing medicine for this difficult to treat cancer. Over the last decade, our surgeons have pioneered a new method that removes only the affected cartilage in the larynx. Home to the nation’s first fellowship-trained laryngologists, the Grabscheid Voice and Swallowing Center is the only facility in the country offering this cutting-edge technique, which preserves the patient’s natural anatomy and ultimately allows them to lead more normal lives.

Symptoms of Laryngeal Chondrosarcoma

The larynx is an organ in the neck that helps us breath, produce sounds, and protect our lower airway from obstructions. This delicate structure is made up of nine different types of cartilage. When laryngeal chondrosarcoma develops these cartilages, the tissue slowly begins to expand and compromise the laryngeal skeleton it is suppose to hold together. Over time, this affects a patient’s ability to speak, eat, or breathe.

Since the symptoms of laryngeal chondrosarcoma develop slowly over a long period of time they are often dismissed. Make an appointment with your physician if you experience any of the following:
* Change in the voice, such as prolonged hoarseness
* Difficulty swallowing
* Trouble breathing
* Feeling like there is a lump in your throat
* Coughing up blood

Diagnosing Laryngeal Chondrosarcoma

Patients who present with symptoms of head and neck cancers are given a thorough examination. Video laryngeal stroboscope is a minimally invasive procedure that inserts a scope with a camera into the throat to visualize the larynx, vocal cords, and relate structures. This diagnostic tool is used to observe changes that could indicate cancer such as a bulb from the expansion of the cartilage or a change in the way the vocal cords vibrate. The larynx is often difficult to biopsy. When changes are found on the stroboscope, high-resonance imaging including CT and MRI scans are typically used to make a definitive diagnosis.

Partial Laryngectomy Surgery Offered Exclusively at Mount Sinai

Laryngeal chondrosarcomas need to be surgically removed. Research has found that therapies used to treat other types of cancer, such as radiation, are generally ineffective. Before surgeons at Mount Sinai developed an alternative, the traditional surgery for Laryngeal chondrosarcomas was a total laryngectomy—a procedure that removes the larynx entirely. However, this life-altering surgery drastically changes the anatomy. Patients need to learn to speak and breathe
through a new opening in their neck called a stoma. The procedure used to create this hole is connected to a tube attached to the windpipe called a tracheostomy. Instead of removing the entire larynx only the affected cartilage is removed, and the diseased portion is rebuilt. The laryngeal framework is a delicate structure when it is taken out, the cartilage has to be replaced or it will collapse entirely. To reconstruct the cartilage, surgeons at Mount Sinai typically take bone from the patient’s fifth rib. The bone is shaped to match the removed cartilage, wrapped with tissue harvested from the thigh, and set into place.

Outcomes of Partial Laryngectomy
Experts are currently following nine patients with laryngeal chondrosarcomas from all over the U.S. who came to Mount Sinai to receive care. Most were told by other institutions that laryngectomy was their only option. Patients who have partial laryngectomy will have a temporary tracheotomy while the airway heals and stabilizes. However, within one year or two, every participant in the study was able to have their stoma removed. So far, all of the surgeries have been successful with none of the patients requiring a follow-up total laryngectomy procedure. Researchers are continuing to monitor their ability to breathe, swallow, and speak — both before and after the procedure — as well as disease recurrence.

Make your Sonesta Hotel Reservation
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Speech-Language Pathologist................................... $200.00 each
Graduate Students.................................................. $80.00 each

First Attendee (Please Print) ........................................ $_________
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Second Attendee (Please Print) ..................................... $_________
Laryngectomee ________ yes ________no.

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City________________________________State/Providence_______Zip__________
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Atlanta, GA 30309

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Voice Institute Updates
By: Caryn Melvin, VI Director

The Voice Institute is looking forward to seeing everyone at the 2022 conference. The agenda is still firming up, but we can state with certainty that it will be an exciting conference with many new faces joining the faculty and several favorite faculty members returning. Here’s a peek at some of what is on the agenda.

Della Mann, MSP, CCC-SLP from Levine Cancer Institute will be speaking about bodily changes following total laryngectomy. Alissa Yeargin, MSR CCC-SLP from ENT Associates of Greenville, SC will be joining us and giving talks on swallowing disorders and the importance of a team approach to laryngectomy management. Laura Sprague OTR/L, CLT-LANA will be speaking on lymphedema management and shoulder issues following reconstruction. Laura is currently working at Sentara Granby Therapy Center in Norfolk, VA. Lindsey Beardsley and Kacie Gamm from Carolina’s Medical Center will be presenting a talk on pulmonary health in total laryngectomy. Linda Stachowiak MS CCC/SLP BCS-S will be discussing travel tips for laryngectomees as well as TEP trouble shooting and the effects of extended reconstruction on voicing. Stacey Brill will join us again this year and will be presenting a talk on starting up a head and neck cancer program. Dr. David Estores, MD will present talks on GERD and esophageal stricture. Cindy Gordish, MS Ed. CCC-SLP will be speaking on TEP speech basics, augmentative alternative communication and oral and dental challenges following cancer treatment. Susan Reeves, M.Ed., CCC-SLP returns this year to share her expertise of esophageal speech and lead the esophageal speech groups. Anne Ammenti will be sharing her experience with blended foods for those with chewing difficulties and other oral stage swallowing issues.

In addition to the presentations, we will have many hands-on opportunities. We will have break out groups for each method of communication where you can learn the basics or learn more about honing your skills. On Friday afternoon we will have an outing where there will be an opportunity for attendees to interact with each other out in the community in a more social and fun environment. Who says learning can’t be fun?

What sets the Voice Institute apart from other educational opportunities is the learning environment. Attendees include persons with a laryngectomy, their family members, graduate students, speech-language pathologists, and allied health professionals who learn side by side and from each other, sharing their unique perspectives.

More information on the agenda, as it becomes available, can be found on the IAL website and Facebook page.

We hope you can join us this year!

Raffle Baskets 2022
By Susan Bruemmer, M.S., CCC-SLP, retired

As a newer member of the IAL Board, I am excited to participate in planning our 2022 meeting in Charlotte, NC June 15-18, 2022 at the Sonesta Hotel- Charlotte Executive Park. We usually have a silent auction during the meeting that is made up of donations from the local host club. That is a big undertaking. I would like to see Raffle items and/or baskets from any person representing their hometown club who attends the annual IAL Meeting/Voice Institute in 2022. In 2020 I had gotten confirmation from clubs in California, Texas, New Mexico, Washington, Virginia, and Arizona. Since we have not met since 2019, I hope those clubs will still be represented at the 2022 meeting and will again confirm that they are willing to participate in this event. We could use a few more baskets representing attendees' local areas. My club in Kennewick, WA is already planning to put together a Washington basket so we can let people know about our area of the country (there will be food involved). If there will be no member attending from your local club, please think about donating a basket anyway and sending it to: Helen Grathwohl, 477 Plummer Dr., Chesapeake, VA 23323-3130.

We would love to have all clubs represented. Please let me know if your local club can help out. It is a great fundraiser for the IAL. Thanks in advance.
John Ready is a name that is known by many of the laryngectomy community for his selfless assistance to many. He started the “Foundation for Voice Restoration.” Through the Foundation he hosted the “California Laryngectomy Conferences” He organized and addressed Speech Language Pathologists at many universities. He presented at many conferences and symposiums around the nation. He advocated on the national level for better medicare reimbursement of tracheoesophageal prostheses and other necessary supplies for laryngectomees. John also served on the Board of Directors of the International Association of Laryngectomees for several years. Several hospitals called upon John to visit new patients, both before and after surgery. He was always ready and willing to help anyone that needed any assistance. He even went into a prison to help a laryngectomee there.

On a fun note, John earned the grand title of “First Place Winner” at the Sin City Laryngeal Karaoke contest in 2019. He sang “Mack the Knife” with a scope down his nose! You can check it out on youtube!

John lost his home to the California wild fires this past year and has bravely been fighting a new cancer for the past five months. He will fondly be remembered and missed by all that knew him.

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