QUARTERLY

NEWSLETTER

INSIDE THIS ISSUE

Our first in person meet in Scotland

Date: Thursday 24th April 2025
Time: 1 — 4pm
Place: The Golden Lion Hotel, Stirling
(https://www.thegoldenlionstirling.com)

Atos and Oracle Head & Neck Cancer UK will attend alongside a MacMillan Advanced Clinical Nurse Specialist, a Clinical Nurse Specialist, a Speech and Language Therapist and a Dietician.

My local Lary Club members will be in attendance and are excited to meet more lary's from across Scotland.

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Your closest train station is Stirling. Closest bus station is Stirling. Both just a 5 minute walk but for anyone who can't manage, I am happy to collect and drive you up to the venue. If you could let me know asap, we can work out how many trips I need to do!

There will be a short presentation followed by a buffet and lots of time to chat and get to know one another and ask questions to our experts.

Steff’s Story

In January 2022 at age 29 I was diagnosed with Laryngeal Cancer.
I had been suffering from a hoarse voice in May 2022 and had managed to be seen by an ENT specialist in June. I was then diagnosed with silent reflux and was prescribed reflux suppressants such as Gaviscon. For the next few months I would continually take things like Gaviscon multiple times a day in the hopes that it would improve the condition of my voice. For a little while it did feel like there were small improvements but my voice still remained hoarse. Over time though my condition started to become worse and by October I ended up losing my voice completely. I had also begun to take notice of a few new developments in my body. I had started having difficulty breathing whenever I exerted myself even just a little. I had also found a lump on the side of my neck. Another trip to see my GP and I was informed that because an ENT specialist had seen me within six months then the chances of me getting another appointment were slim. I was prescribed 4 weeks worth of Omeprazole. My voice returned slightly during those 4 weeks but was still incredibly hoarse. After my follow up appointment with the GP they sent a request for me to be seen by ENT again. At this point I started to take notice of my weight. Since being seen in June I had managed to lose almost 20lbs. At first, I thought it could have been diet changes that I had to make to help with the supposed acid reflux but the intensity of my weight decline really started to alarm me. At this point I had also stopped being as active as I used to be, I went from working out 4 days a week to none. I did everything that I was told to help stop the symptoms of acid reflux and nothing was working. Then in January I lost my voice completely again. That is when I really started getting desperate. After discussing my options with my girlfriend Lauren we decided that it would be best if I went with private medical care, something I thought I’d never have to do in my life. I was seen on January 13th (Friday the 13th of course) and underwent another endoscopy. It didn’t look good. I was told the possibility of what it could be and got booked in for a CT scan and a biopsy. The next few days I tried my best to keep it out of my mind. Nothing was confirmed so there was no point worrying. January 23rd was my biopsy. The hospital kept me in overnight in order to monitor me in case any swelling occurred after the biopsy. The next day I spent most of it on the ward in hospital waiting to be discharged and sent home. Literally just as I was discharged and about to leave, my results had come back. It was Cancer. Stage 4 laryngeal squamous cell carcinoma that had spread to my thyroid and potentially my lymph nodes. However, it was treatable. But it required me to have a complete Laryngectomy. The CT scan results had shown that I only had 4mm worth of breathing room left and it would only get smaller as time went on. Surgery was on 2nd of February. I received a letter with an NHS ENT appointment from the second referral before going private for the 1st of February. The realisation hit me that if I had waited for the NHS, then I probably wouldn’t be here today. Just a warning that the next part might be a little graphic. Surgery turned out to be complicated. Due to my windpipe being so small I wasn’t able to be intubated normally and the plan was to do so whilst I was semi-lucid. The idea was that I’d be given anaesthetic to help loosen me up and then they would attempt intubation. Unfortunately, I passed out from the anaesthetic. This caused my windpipe to almost completely close. An emergency tracheostomy was performed in order for me to receive oxygen. This is where more problems happened. Even with the intubation tubes in, my oxygen saturation levels were only at 60%. The surgeons believed that this was due to a possible collapsed lung. To rectify this they pierced my rightt lung. This didn’t help. I did however now have a collapsed lung. It turned out that both intubation tubes had found their way into only one of my lungs and had to be quickly reinserted. By this point I had been without a steady flow of oxygen for over 2 minutes. I was told that this should have caused me to suffer brain damage to the extent of having a stroke. They expected me to wake up without motor function in my arms and legs and also to not be able to recognise people. By some absolute miracle, this wasn't the case. It took 9 hours for the surgery to be completed. Full Laryngectomy, partial thyroidectomy and 100 lymph nodes removed. The first thing I remember after waking up was being told I had to have a drain inserted into my lungs. Another not so pleasant experience. I was then wheeled off to a high dependency unit for the next 2/3 days. This part was a bit of a blur for me (probably due to the amount of morphine). But after those few days I was eventually taken to my home away from home, Ward 26. I really can't express how grateful I am for every nurse and doctor that worked on that ward. Every one of them were a light in one of, if not the darkest period of my life. I spent the next 3 weeks recovering in hospital. Every few days a tube would be removed and I’d slowly start feeling a bit more human. One tube in particular still gives me nightmares but I’ll leave that to the imagination. I was told post surgery that the margins were negative but they would still recommend radio/chemo to be as safe as they could be. Over time I’d start getting out for walks and doing some stretches and exercises. I had quite a lot of nerve damage caused by the surgery and even now I still struggle with movement in my upper body. I had to relearn how to use my tongue and also how to swallow. I also had to relearn how to speak. Even though my voice box has been removed, I actually have a small

Steff's Story continued..

prosthesis that allows me to speak. I do sound quite a bit different now and my singing days are pretty much over (to the delight of many). I then had 6 weeks to recover at home before the next stage of treatment began. 6 weeks of Chemotherapy and Radiotherapy. I had to say goodbye to some teeth before I could begin it too. I also had to have a feeding tube surgically put into my stomach to help with feeding during the treatment. This took two attempts which was inconvenient but I did get given some fentanyl on the first attempt so it was still a fun time. Second attempt was not so fun. All I'll say is don't be awake during a surgery. They did let me listen to Orville Peck during it though, that was nice. The first week of treatment seemed to going well until the weekend. Every Tuesday I would have Chemo and Mon - Fri I would have Radiotherapy. What I didn't expect was a stomach infection caused by the feeding tube. I spent the first weekend feeling absolutely terrible with no appetite whatsoever. I had spent the last 6 weeks trying to put on as much weight as possible before starting chemo and rads and unfortunately, I ended up losing most of what I had put on in the first week due to the infection. I did end up getting some antibiotics which helped clear it up but the next 5 weeks were still unbelievably tough. I think the best way I could describe it is like having a 6 week hangover that doesn't go away no matter what you do. It honestly made me miss real hangovers. Around week 3 the radiation started to do the thing I was dreading the most. My hair started falling out. Its a pretty vain thing to be concerned about but it honestly was one of the worst days for me. I completely lost my beard and about half the hair on the back of my head. Even now my beard still hasn't fully grown back and probably won't ever fully return to what it was which was a really depressing thing to come to terms with. Once the 6 weeks of treatment had finished there was a little bit of time where things got a tiny bit worse but after the 2 week stage I was already feeling 100 times better. I decided to not bother waiting around any longer and get back to living my life as normal as I could again. At the end of treatment I was the lightest I had been since I was a teenager. The year prior I was 40lbs heavier. One of the hardest things I had to deal with was looking at my reflection and not recognising the person looking back. Since completing my treatment my focus has been to try and get back some part of who I was beforehand. I'm back at the gym which has greatly enhanced and sped up my physical recovery, I am very passionate about fitness and have used this as a challenge to push myself even further than I did before (who says larys can't lift?!). I work full time, have bought my first home with Lauren and we have a little Border Terrier Seelie. I'm out and being as sociable as possible, I travel and attend events as normal. I'm using my new voice and speaking to strangers to try and feel more comfortable with who I am now. I have also used my experience to help and educate others, I have spoken with multiple patients who are also having the surgery as well as medical students and district nurses.

I never could have made it to this stage if it wasn't for the amazing support of my family and friends. I want to thank every single person that helped me in any way they could including the Life After Lary group and many individual members specifically. Many of your stories gave me hope of what my life could be after surgery so thank you for sharing them. Even if it was just words of encouragement, I appreciate it all immensely and can only hope to repay it all back someday.

Paul’s Story

December 2015.
My voice had been knackered since early in the year, like a typical man I ignored the obvious, ignoring the nagging of my family & friends. I eventually bowed to the pressure paying a visit to my friendly GP. In those days you could get a GP appointment without having to give your inside leg measurement to the receptionist.

He immediately put me onto the 2 Week Pathway which involved a CT Scan followed by a Biopsy. The Biopsy all went a bit pear shaped as I reacted badly to the General Anaesthetic, had a cardiac arrest , “Died” for around 10 seconds apparently before CPR brought me back. Obviously I knew nothing about that episode, frankly when the surgeon was explaining this to me I was still away with the fairies, so it fell to my wonderful wife to take the phone call at home explaining what had happened On Christmas Eve 2015 my wife and I made our way to the old Nissan Huts in the Royal Berkshire Hospital to get the results of the biopsy, secretly I think we both knew what the result was going to be. We sat down at about 4pm with my Consultant and our CNS Jo, who has since become a trusted family friend. T2 cancer of the throat, but “We think you’re worth saving!” said my consultant having identified that I had a bit of a dark sense of humour. The treatment would be 30 sessions of RT and 6 of Chemo which would begin early January 2016. Our next job was to break the news to the kids, we’d thought about getting Christmas out of the way, but decided that was going to be a challenge. So, with typical tact we sat them down and I said “Hey kids, we’ve got some news, Dads got cancer, ho ho ho Happy Christmas”. That Christmas turned out to be a total scream, we had family down with us, didn’t leave the table until close on 10pm and dented the wine cellar. Stupidly I agreed that I’d be on the pitch with my son for the annual Boxing Day rugby match in December 2016 if things went the way we hoped they would. Treatment started mid January after I’d been through the fine needle biopsy, mask fitting and getting a tattoo. I’d always presumed that Chemo would be the killer and I’d float through RT. How wrong could I have been. I struck up a good relationship with the Radiographers, I think taking cakes in for them each Friday possibly helped. They knew when I wanted to chat, they knew when I just want to curl up and be left alone. The last session of RT was so tough, I dragged myself out of the Berkshire Cancer Centre, mask under my arm, drove home, lay on the sofa and fell apart for a few days. I could hardly eat, sleep wasn’t happening, my voice had gone on holiday. However, over time my taste returned, my voice got better life became normal. I vividly remember the meeting with my Consultant in May 2016 when she confirmed that the cancer had been zapped! We promptly booked a holiday in Corfu to stay with friends, albeit probably about two months too early in the recovery process. Life was great for about 10 months, my employers, Santander, had been fully supportive of me, allowing me to take time out when needed. My kids were excelling at their studies........ I pulled on my boots for the Boxing Day rugby match, making a 10 minute cameo appearance, ... then, the voice began to fail. May 2017 and another biopsy. “Paul, I’m so sorry, it’s back and this time surgery is the only option!”. I’d never heard of a Laryngectomy, had no idea what the future would hold. Would I be able to speak, eat, breath, live a life? I was offered the chance to meet someone who’d been through the process, but stupidly declined. I’ve since seen three patients who were due to go under the knife, I like to think I’ve helped them. I went under the knife in June 2017 in the Churchill Hospital, Oxford. The next 5 days were a challenge, initially because the person in the bed opposite me rang the nurses bell every five minutes as well as insisting on playing films on his laptop at full blast in the middle of the night. I was thankful to be moved to my own room which was better than some hotels I’ve stayed in. I coped fairly well with the change in my body, communicating via writing in a note pad (which I still have). When I was allowed to I started walking the grounds of the hospital, the nursing staff often getting pee’d off that I wasn’t in my room when they needed me. Sleep was still a challenge, a couple of nights I sat at the nurses station for a couple of hours, having a chat. When I say “Chat” I of course mean I listened and wrote. I spent a lot of time writing my blog which I published on a Friday evening. I found that whilst I couldn’t speak, I could express myself through writing.

I’ve always been a bit of a foodie, once I was deemed watertight I began taking myself down to the hospital canteen to buy breakfast, much better than the rubbish stuff being served to me. My wonderful wife started bringing me in food for home, spag bol, chilli, and the like. I’d heat it up in the kitchen microwave, take it back to my room, fire up Netflix, then take 30 minutes to eat the smallish portion. Welcome to life as a Lary. I was released 14 days after being admitted, the fun was about to begin. I remember my first venture into town and having to clean out my valve in public, the first time I was stared at in public, the first time my valve leaked. I was incredibly lucky to have a wonderful SLT Team at the RBH, they supported me throughout the early days, came up with suggestions to help the valve life, and importantly recognised that I’m a pretty resilient person. As I mentioned, my employers were very good to me, never putting pressure on me to get back to work, unlike some employers I’ve heard of who try to “manage out” any employee with a cancer diagnosis. My role was as a Corporate Recoveries Manager (glorified Debt Collector), I was customer facing, working from home.

Paul’s Story continued..

The job involved often having to give bad news to customers, a few used my new disability (?) as an excuse that they couldn’t understand me. By the time we got to late summer 2019 I was finding it harder and harder to get out and be front of house as I needed to be. Santander were great, an agreed payout was offered and taken. For the first time in 35 years I was out of work. I intended to have six months off work, recharge the batteries and find something else to do. Then along came COVID. Initially I was classed as highly vulnerable, my wife is a nurse and was working in Respiratory at the time, she was moved to back office duties to protect me. Slowly but surely I sussed out that my HME is probably a better protector than anything other than a medical grade mask. I’ve come to recognise now that I’m unlikely to have gainful employment again. I get tired easily, would struggle to work 8 hours a day, and who would look after the medium sized dog called Neville? I did spend a bit of time being “Fishy Van Man” doing deliveries for my local fishmonger, but found driving for six or seven hours to be beyond me after a few months. It would be quite easy to fall into a malaise if you let being a Lary get to you. I’ve tried as much as possible to embrace things. I appeared three times on the Victoria
Derbyshire Show banging on about Larys, my son and I were also contestants on BBC Pointless, I still say we were robbed! I applied for Masterchef, getting to the final interview which wasn’t great as my voice was awful on the day. My days are spent walking my dog, dreaming up new recipes to feed the Current Mrs C (40 years and counting, I like to keep her on her toes) when she gets back from the hospital and photographing anything I can find of interest. My friends and family respect me for what I am, they don’t look twice. I’m a great advocate for Hands Free HME’s if they’re suitable, they make me far more confident talking to strangers. I avoid “Noisy” social events these days as I can’t really make myself heard.
Life as a Lary isn’t always easy, but…… It’s better than the other option.

Bill’s Fundraising

On 12th April Bill Wilson (larynxlad) led a team up Mount Snowden in North Wales in aid of Life after Lary. After much delay due to traffic and travel from Essex, Bill and the team met with Jon at the foot of the mountain. Jon was there to support them as they have put so much into supporting us. The climb started around 12.45 and they all made if to the top and down again some 25,000 steps later. On the ground weather was cloudy with light winds and 16^0 at the top it was -2 and winds reaching 35 mph. The group finally returned to Essex at 02.30 the following morning. We cannot thank them all enough for doing this for LaL and so far over £1,600 has been raised.

Later this year a charity football match and golf day are planned along with a grand draw raffle - all to raise money for LaL.

If you can help plan days as in a netball match or bake sale or something else to help raise funds, please let us know and we will support you. If you can help in anyway to arrange any events please let us know. We would really appreciate it.

Watch this space for times and dates of future events. We would like to give a special thank you to Lili at Atos Medical UK for their support In supplying t-shirts and hats for the event and to slo drinks for providing a windshield jacket for Jon.

We would like to take this opportunity in sending a massive thank you to everyone that has donated so far. Every penny matters!

Available to buy

As you may know we now have a number of items available to buy to help keep Life after Lary running. Any monies raised helps us to keep providing care packages and other support for patients.

I BREATHE THROUGH MY NECK
Oxygen to be given via neck stoma

Please be patient.
I cannot always voice straight away.
I may sound different or use a communication aid to help me speak.
You do not need to raise your voice, I can hear what you say.

I BREATHE THROUGH MY NECK
First aid oxygen to be administered via neck stoma.

My name
Emergency contact
Phone number

FaceBook - LifeAfterLary UK
www.lifeafterlary.co.uk

Please contact Jon if you would like to purchase anything.

Next Zoom: Thursday 1st May 6.30pm (UK Time)

Further details available in the 'featured' tab on facebook.

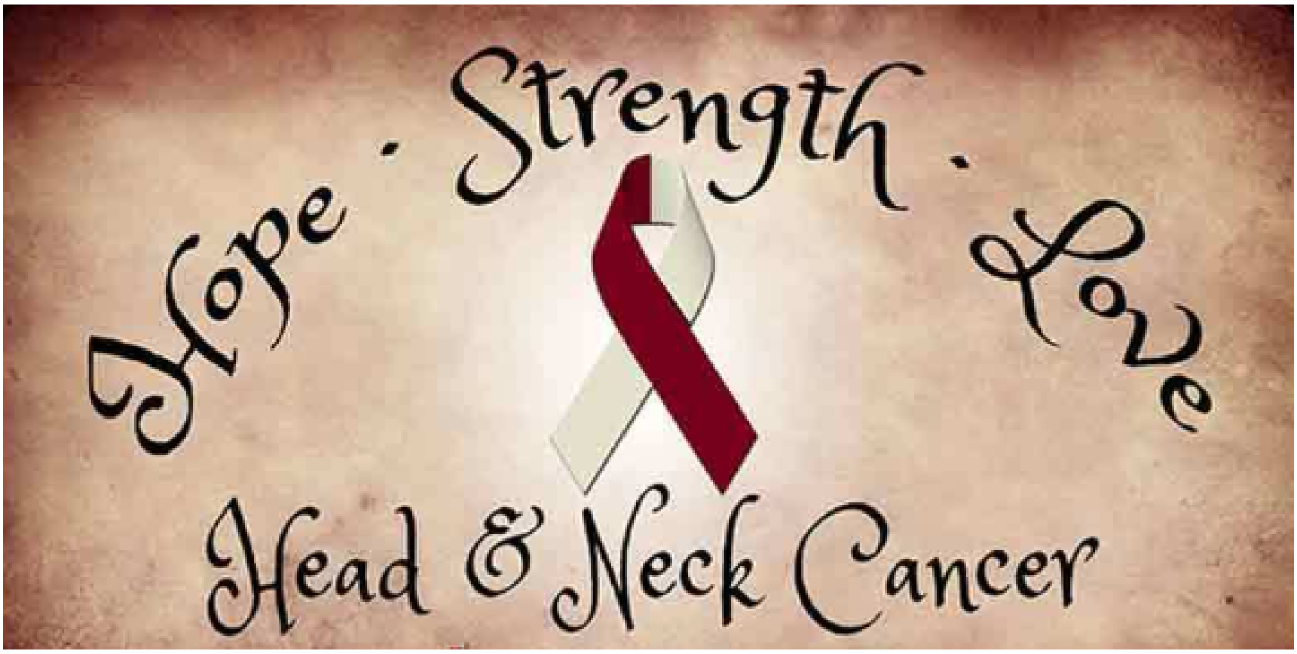
If anyone would like to join but is unsure of zoom and how it works please contact Jane who would love to help to ensure you can join in.

Some sad news

Unfortunately I have some sad news to share with you all. You may already be aware that Kathy Grosvenor, Ronald Cooke, Melanie Ruiz, Dr. Itzhak Brook, Keith Harris and Steve Rice all lost their fights with cancer in recent months.

They will all be sadly missed by the laryngectomy community worldwide.

May they rest in peace.



Welcome to Atos Care

An integrated care and distribution service for people with a laryngectomy in the UK.
Atos Care is a comprehensive support service that includes a team of CQC registered nurses, dedicated to making life easier for people living with a neck stoma.

The Atos Circle of Care

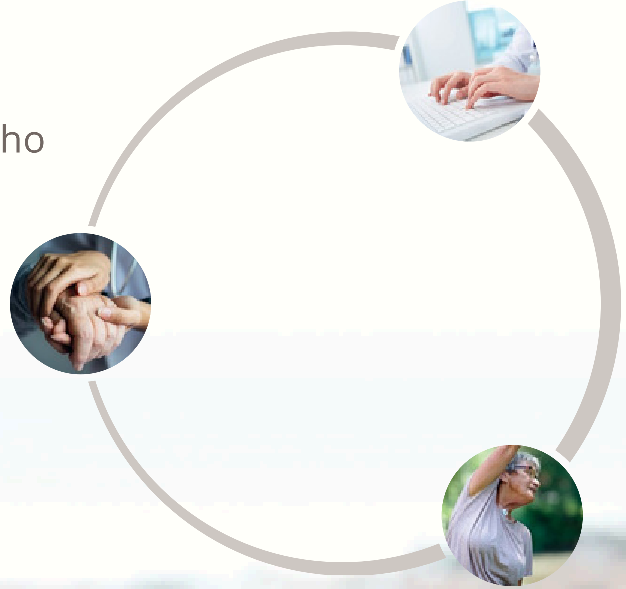
Best Start: Get off to the best start in life after a laryngectomy.

- Enhanced support for your first six months from our Welcome Team of CQC Registered Nurses
- A welcome pack and a welcome call
- Practical tools and equipment to make life easier, including a complimentary care bag containing a range of helpful items
- Regular liaison with clinicians for joined up care

Inspected and rated
Good
Care Quality Commission

Connection hub: Stay connected to those who know and understand.

- A dedicated Customer Care Representative
- Personalised service - you choose how and when you hear from us
- CQC Registered Nurses to support you in your daily routines, in close partnership and communication with clinicians
- Educational events in the community for people with similar experiences



Care delivered: Bringing the right products and care your way.

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- Rapid, reliable delivery
- Discreet packaging
- Convenience orders by subscription

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Breathe better,
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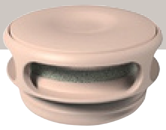
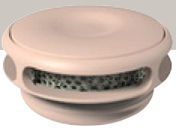
- Reduction of mucus
- Reduced coughing


Home
HME

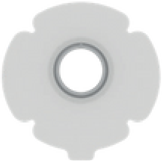

Go
HME


Night
HME


Energy
HME


Protect
HME

FreeHands
HME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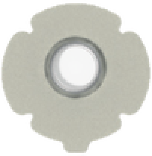
Adhesive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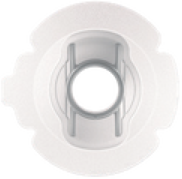
Stability
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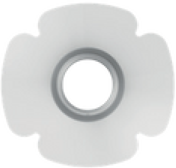
Night
Adhesive

Breathe better, whatever you do

The Provox Life™ system was developed on the basis of thorough research, and is designed to address the challenges that you experience with HMEs and attachments.

Designed for people with a laryngectomy, the system offers a complete, flexible solution that allows you to experience a personalised routine, no matter where you are on your recovery journey.

Please visit our website at **www.atos-care.co.uk** or call us on **0800 783 1659** for more information on how Provox LifeTM can improve your quality of life.

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