



Newsletter March 2023

Dear Friends

We have been very pleased to be able to hold Christmas Lunches after the two year break due to Covid restrictions. Plans are also going ahead for summer events too. As I was sitting enjoying the atmosphere at our event here in Halifax I could really feel my late father's presence as I remembered how important he felt such occasions were to help life return to normal after laryngectomy. We were pleased to welcome new members to both the Halifax and Swindon events.

Thank you to everyone who responded to our appeal for donations in the September 2022 newsletter. A total of £1,445, plus Gift Aid where appropriate, was raised. We are also very grateful to new member Raymond who has secured donations from St Nicholas Lodge in Scarborough for us.

We are pleased to welcome new member Jayne following her surgery in November 2022 and thank her for sharing her experiences with us.

Best Wishes
Carole Stainton, Trustee

Can you hear my voice Screening



David Webb of Oldham Quiet Ones support group reports:

The support group in association with Atos secured the first screening of the film "Can You Hear My Voice" outside of London. The film was shown at a reception at the Gallery Oldham on Saturday October 1st. We had a fantastic day, everything went perfectly.

We had a great turnout and we received some lovely feedback about the day. Everyone agreed it was a very moving, inspirational and up-lifting film about laryngectomees.

We are very grateful for all the help Atos and Gallery Oldham gave us in making the special day possible.



Contact us:

Website: www.cancerlt.org Email: info@cancerlt.org

Address: CLT, PO Box 618, Halifax, HX3 8WX

Charity Registration No 326653



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Presentation by St Nicholas Lodge

New member Raymond Tristan Brown who is Worshipful Master of St Nicholas Lodge 2586 of Freemasons in Scarborough kindly arranged a donation of of £500 to the charity from their Benevolent Fund.

Subsequently at a lodge meeting in November Ray was asked to submit a application for match funding as there was a possibility that the Provincial Freemasons Charity York and North & East Ridings could match fund it.

The application was submitted by Cedric Thornton as Lodge Charity Steward and it was accepted hence the presentation of £1000 was made to the charity at the York Christmas Lunch.



Christmas Lunches

Christmas lunches have been held in Blackpool, Halifax, Swindon, and York. The Blackpool lunch was arranged by Sandra Waddington who is also planning a Summer Lunch there too.

Member David from Oldham support group reports:

I am emailing you thanking you for the wonderful day we had at this year's Laryngectomee Trust Christmas lunch in Blackpool.

As always, it was a fantastic day. Sandra does a brilliant job organising everything and we always look forward to meeting everyone. All our group thoroughly enjoyed it and would like to pass on our thanks.

As usual I've taken some photos and attached them and hope you agree we all look like we're enjoying ourselves!



Loch Lomond Cruise



Ann Muir arranged a September cruise on Loch Lomond for the members of Speak Easy Lanarkshire support group.

After the cruise they then had lunch at the Inn at Inverbeg, before heading off for some retail therapy at Lomond Shores Outlet.

Farewell to Geoff

We were very sad to learn that Geoff Read passed away in hospital at the beginning of January.

Since Geoff moved in to the Chelsea Hospital in 2020 he had been a regular contributor to our newsletters.

One of his most recent challenges was to take part in the Veteran's Banger Rally in aid of the armed forces charity SSAFA which left Dover on 13 September to travel to Gibraltar. All participants had to travel in a vehicle costing less than £500 so they bought a 2004 Toyota Corolla offered for £450 and after a challenging journey they arrived in Gibraltar.

After their return Geoff and co-driver Chris O'Connor were awarded the Queen Elizabeth II cup for their participation in the rally. Chris reports that Geoff was extremely pleased with their success. Another pensioner Trevor Rafferty also took part in the rally and the photo shows Chris and Trevor, with Geoff represented by his photo, with the 3 awards they collectively won.

Chris intends to drive the car in the 2023 Veterans Banger Rally back to Gibraltar calling their team The Geoff Read Memorial.

He will be raising funds for Blind Veterans, Royal Hospital Chelsea Outreach and Back on Track who have asked him to donate the car for their auction.

It has been a great pleasure for me personally to become re-acquainted with Chris who served as one of our local councillors and was Mayor of Calderdale from 2001-2. We presented a copy of the reprint of the original version of Laryngectomy is not a tragedy to him in his role of Mayor back in 2002.



Speak Easy, New Year Lunch

Members of the Lanarkshire Speak Easy Group enjoying a New Year lunch at Wishaw Golf Club arranged by Ann Muir.



Summer Lunches

Summer lunches are being planned for Blackpool and Scarborough. The Blackpool lunch will be held on Sunday 11 June 2023 at The Imperial Hotel and is being arranged by Sandra Waddington, 76 Rutland Avenue, Poulton-le Fylde, FY6 7SA Tel 01253 899531 email waddington46@yahoo.com

If members wish to stay overnight you just need to quote the name of the event and date to get a discounted rate which has been agreed by The Imperial. Guests will need to call the reservations department on 01253 623971.

The Scarborough lunch is being arranged by Dawn Potts. Address: The Granary, Hull Road, York, YO19 5LE. Tel: 01904 489360, Mobile: 07947624421, Email: dawn.potts@hotmail.co.uk.

Trustees Report - year end January 2023

In last years annual report I expressed the hope that we could return to a more normal level of activity during 2022. Thankfully this has proved to be possible.

Although there are still many Covid cases in my area, it was possible to hold Christmas lunches again. The feeling of relief and joy at being able to meet in a comfortable, relaxing atmosphere again was particularly precious.

However, it did bring home to me the difficulties that hospitality venues have had to face during lockdown. We moved the Swindon lunch to a different venue as a change of ownership meant that our previous venue was no longer suitable. The new host could not have been more welcoming.

We had three guests who had not had the opportunity to meet other people who

It was so encouraging to see them chatting and finding out all those tips that only another person in a similar situation can know about. It was wonderful to see old friends again who had missed the lunches as much as we had.

2022 was the first Christmas that we no longer had our beloved sister Wendy with us. The Christmas lunch was an important part of her calendar. Thankfully, her daughter Sarah and husband Bill were able to attend both the Halifax and York lunches just as she would have wished.

Although we remain cautious about social events we are able to plan for these to take place in 2023 with renewed confidence. We owe a real debt of gratitude to all the doctors, researchers and others who worked tirelessly to produce such excellent vaccines so quickly.

As I am writing this, we are in the grip of a very wintry spell which has made me think of the difficulties facing those with large heating bills.

It is essential that anyone with health issues is able to keep warm. If anyone is in a difficult situation we would encourage them to contact us to see if we are able to help with a grant.

We look at all requests quickly and will try to help if possible.

We do hope that 2023 will be a peaceful and healthy year for you and your family.

Ros Oswald, Trustee

Laryngectomy research



- Are you a person with laryngectomy?
- Do you use an electronic larynx?
- We want to hear your views!

Please scan the QR code, or email a.sweetman2875@student.leedsbeckett.ac.uk for more information.

The Beautiful Blue

Author Lucinda Hart introduces her new book.

Au revoir. The last words my father Chris said to me the night before his laryngectomy. It wasn't just a laryngectomy: He had to have his thyroid and parathyroid removed as well, and part of the pharynx. He was in theatre for twelve hours.

Then, back in 2016, I was still a wannabe author. I had been attached to a top London literary agency for a year but nothing had come of it. I was still writing novels, one after another, in the hope that someone might be interested in something I wrote.

And then, watching my father come to terms with his tracheostomy, I knew I had to write about a laryngectomy patient. That wasn't enough on its own, of course. I had to create a whole world, and so I turned to another area where you have to learn to breathe differently: swimming. I'd gone swimming as a child and never been able to let go of the float. I had never had any confidence – or a decent teacher. I tried again at 21 just before I went to university, by joining a group for adults. Again, it was a failure.

At the age of 39 I decided to learn to swim once and for all, and this decision coincided with my father's surgery. I realised there were similarities between the two situations: an acute awareness of the airway, and

a new way of breathing. (I can now swim!)

The manuscript was originally called Saturations on Air. The laryngectomy patient, Guy Lovell, is a radio presenter, someone who relies on his voice for his job, and suddenly that is taken from him. Meanwhile his wife Heather is learning to swim as a middle-aged woman.

The book follows the lives and loves of the members of the adult swimming group, as well as Guy's terrifying journey through diagnosis and surgery to tracheostomy and a new voice.

I wrote the book alongside my father's experiences, although I spared Guy the worst of what happened to him.

This was a book I never thought would interest any publisher: too odd, too gruesome almost. But shortly afterwards I was taken on by Vulpine Press for another novel, The Broken Air, and I showed them this manuscript. They said yes and I was overwhelmed. The book meant so much to me as by then my father had died and I was struggling with my bereavement and the experiences we as a family had gone through. My mother had lost her husband and my daughters their granddad. My littlest one was born only months before he died and will have no memory of him.

I worked with an amazing editor to get the book into a



better shape; the title has now changed to The Beautiful Blue and it is coming out on 30th March. I know spoilers are frowned on, but it is important for me to say that things do not work out happily-ever-after for Guy.

Please join me on Facebook
Lucinda Hart Author

CHRISTOPHER JOHN HART
1946-2017
REST IN PEACE



Introducing New Member Jayne

A Big Cheery Hello to all Laryngectomees and those just embarking on their journey. Firstly I like to say a heartfelt Thank you to Carole for the kindness and support she has extended to me at what initially was "and I say was" a very dark time for me to both cope and come to terms with. But not being a quitter I gave myself a good talking to and listened to those around me which I'm pleased to say worked wonders as I'm happy to say that I have a whole new Future ahead of me.

Being a Lady that is fast approaching her Big 60th Birthday "which I have every intention to celebrate to it's full" it came as quite a shock that I learnt that the much dreaded "C" had caught and gotten hold of me well and truly.

It all started back in late Sept 2021 and quickly I found myself on the path of a very rigorous regime of 12 weeks, 5 days a week radiotherapy and 4 weekly Chemotherapy. For Cancer of The Voice Box itself.

The biggest initial shock to me after a lifetime of looking after my teeth and having virtually a full mouth of them I was told it was necessary to have not just one or two removed But Six and this was to minimize future complications due to the radiotherapy, so picking myself up from the floor for rather the Dentist's chair I thought ok if it's to be I'll just

have to suck on my food!! Which at this stage didn't seem so bad but little did I know it was only going to be a matter of weeks before I was fitted with a feeding tube ,Via the abdomen rather than the nasal route " a decision I was glad of further down the line".

Things didn't go so well for me not only was the cancer far more aggressive than first anticipated but I also had an extremely bad reaction to both the radiotherapy and the dressings that were used so much so that I lost layer upon layer of skin that it looked like a chainsaw massacre every time the dressings had to be removed for treatment But I never gave in.

Positivity was the key although it felt like I would never have a neck that would be recognised again I just kept the end goal I sight. One of the things that helped me focus other than the great support network around me was the sight of little children going through unimaginable treatments but still in their innocence were able to smile.

Skipping forward and after a what was classed as a suitable time period on my post checks it was evident that the treatment had not been successful I was still on a feeding tube and also at the point that my ability to breath sufficiently to sustain life was becoming impossible (not something that could be ignored) it was

also now 16 months since I had experienced the eating of food and now 6 weeks since I could even swallow liquid! So, it was time for surgery.

Enter the "New life as a Laryngectomee" and the introduction of Carole. I would be lying to say that I wasn't scared by the prospect I was terrified and I didn't know of anyone that had experienced the process that I could turn too. However the team at the hospital's I was attending couldn't have prepared me any better. So on the 17th of November I went under the knife I had to have both my Food and Wind pipes replaced which hey had to use tissue from my thigh for which has left me with a gorgeous 14" long scar "something to tell the nephew's and niece about in years to come" also for that reason having both replaced I was unable to have a speech valve fitted at the same time !!!



Another shock I wasn't quite prepared for but believe you me you learn very quickly in ways to be heard when you haven't a voice and it's also a great source of hilarity "Christmas charades " were most interesting!!! Which was a festive period I didn't think I would see this year as I was told I'd be in hospital for some 6 weeks but I proved them wrong with grit and determination I was on my way home within 14 days.

I had taken to it like a Duck to Water I had given myself a talking too This was going to be a new way of life and it wasn't going to beat me It was my Life to Live not one that a mere change of the way I communicated was going to determine how I was going to live it.

So I got to celebrate the festive season with my family and friends I got to eat and drink something I apparently should still even now be just getting into doing "That Minted Lamb Dinner that was long awaited for was out of this world as was that first glass of Cold Water".

As far as the next steps I'm waiting for my mechanical voice to be fitted which because of my determination is going to be some 3months earlier than expected, I'm battling a small problem with a constant swollen face due to my Lymph glands having to be removed but I'm told this will get better with time and a bit more practice on the exercises.

However my biggest surprise is in myself when we are faced with adversity if we approach it head on ask all the questions you think of so you are always in full knowledge of the process, use your support network they love to help ,honestly and Stay Positive it's surprising what you can achieve.

I have a whole new life now and a support network second to none and so lucky in the people I have met to date and of course I have the meeting of new friends of the Laryngectomee family to look forward to meeting in the near future.

It was a bit strange trying to put a snippet of my story on paper for you but I hope that it is of some interest and maybe of help even to just one person that is on the eve of such a journey for themselves.

I have added a few piccys showing some recent good times with my nephews and niece at Christmas.

Kind Regards
Jayne Yeates
West Yorkshire



NEW AND IMPROVED



Provox® Life™ Night HME



Provox® Life™ Night HME has been redesigned to improve ease of connecting and disconnecting Night HME from the SecureFit™ connector.

Provox® Life™ Night HME now features a ribbon across the body of the HME with a small indent. This helps guide placement for the index finger when attaching the device for an improved experience.

As part of our corporate values and initiatives to be environmentally conscious, we have changed the manufacturing process for Provox Life Night HME to reduce our environmental footprint.

 **Improved ease of connecting to SecureFit™ connector**

 **Reduced environmental footprint**

Sleep is a key part of a healthy lifestyle, which can help improve your memory, lower stress and help keep your heart healthy. Provox Life™ Night HME (Heat and Moisture Exchanger) helps reduce coughing for more restful nights. It offers high humidification which helps reduce mucus production and coughing, allowing improvements in sleep quality.


Key features:

- ✓ Reduced coughing and mucus
- ✓ Comfortable breathability for nighttime breathing
- ✓ Soft and smooth for nighttime comfort
- ✓ Side openings to prevent occlusion while sleeping when being active



Find out more about the Provox® Life™ Night HME by contacting our Customer Care team or visiting our website:

 **Call us**
0800 783 1659

 **Email us**
info@atos-care.co.uk

 **Visit our website**
www.atos-care.co.uk

