

## Newsletter Sept 2018

*"To help improve the quality of life for all neck breathers"*

### Race Night 2018



Once again we invite all members to take part in our virtual Race Night. For those of you who have not participated in Race Night before, this is what happens: We offer ownership of imaginary horses as an absent owner at £5 per horse, you can name it yourself or we will invent a name for you. These are then made up into races of 10 horses and an Absent Owners Race Card is printed. Samuel Beales, a great-grandson of our founder Sydney Norgate, drew the cover design for the race card. His drawing is shown here. On race day we draw out the winners and a prize is sent to the winner of each race. We also have the raffle tickets at 50p each or £2.50 per book of 5. The First Prize for the raffle is a £100 cheque and in addition there will be 4 of prizes of £25 each. Alternatively

you may wish to make an optional donation rather than taking part in the races or raffle. We do need all requests for horses and ticket stubs by the 17th October to give us a chance to organise everything.

There is a space on the form for you to request extra books of 5 raffle tickets to sell to others. If you fill this in and send it to me I will be happy to send you the requested number of books. Alternatively you can contact Wendy Thompson on 01430871561 to order more raffle tickets. You are under no obligation to sell all of the tickets you request and part books sold are fine. Please remember to order early, as all ticket stubs have to be back by 17th October. PLEASE NOTE THE FORM AND CHEQUE IS TO BE SENT TO WENDY THOMPSON NOT TO THE CHARITY ADDRESS.

We hope you can participate again this year; a form is enclosed for your reply. I hope you will get some fun out of it and that we can raise a useful sum to continue the work of the charity.

If you are making a donation and are a taxpayer, please consider signing the declaration on the back of the Race Night form. It would increase your donation at no extra cost to you. I am pleased to tell you that we have been able to reclaim over £9000 from the Inland Revenue under the Gift Aid scheme so far.

We MUST stress however, that if, for whatever reason, you are unable to participate or do not feel that you can sell to others, that you are under NO OBLIGATION to do so and need not return the books to us. We fully understand that people's circumstances are different, that they may have moral or religious objections and that some of our members are less mobile than others.

Dear Friends

Well after a long dreary winter the summer flowers and hedgerows seem to be extra colourful. I hope you have managed to get away on holiday during the summer and if travelling in the UK have found the confidence of the Travel Guide assists your trip. For those travelling abroad my own recent experiences would encourage anyone with difficulties getting to the aircraft to ask for assistance when booking. No medical proof is required and the staff were very helpful both at Birmingham and in Germany. We were heading to Germany for an exchange visit in Lubeck but unfortunately our departure was delayed by 24 hours in Birmingham due to problems at the German airport. Once there we spent a very enjoyable 4 days with friends including a visit to a marzipan factory.

Our youngest great-grandson is growing fast and is now walking so we will have to have eyes in the back of our heads when he comes for tea on a Sunday.

Race Night will soon be with us and we look forward to receiving your entries. This event is our main fund-raising activity organised by the charity and we thank all those who have taken part in the past. We are also planning Christmas Lunches in various locations and I look forward to meeting local members at York Novotel on 30th November.

Best Wishes, Wendy Thompson, Trustee

## Ann Muir MBE



Ann was awarded her MBE in a ceremony on Tuesday 3rd July 2018 at the Palace of Holyroodhouse in Edinburgh. The MBE is given "For outstanding achievement or services to the community, long-term significant impact, and stand stands out as an example to others." They said at the ceremony it was for services to those with cancer in Scotland.

**Ann describing her thrilling day:**

*Recipients and guests have to arrive before 10am. All have to show ID and invitation before being allowed into the Palace Grounds.*

*We were ushered inside and those being given the award were separated from guests and taken into a large reception room where the Lord Chamberlain outlined the proceedings, and gave instructions on what we should do on meeting the Queen.*

*At 11am we were then led in smaller groups into the large reception room where the ceremony would take place, in front of all guests and where the Countess of Wessex's String Orchestra was playing. One by one we went to receive our award, stepping up to the dais, where we either curtsied or bowed to the Queen, who spoke to each person, congratulating and commenting on what we received the award for.*

*After all the awards, 64 in total, we were ushered out to meet up with our guests and could then stroll on the Palace grounds for a short time. After all the excitement it didn't seem possible that it was all over in just an hour!*

Ann Muir MBE

## Travel Guide 2017



A Laryngectomee's Travel Guide  
to the British Isles  
5th Edition

Supported and Distributed by the Cancer  
Laryngectomee Trust

The Travel Guide provides information for laryngectomees about hospitals throughout the UK and Southern Ireland. The idea behind the guide is to give laryngectomees confidence if they are travelling away from home. If problems arise the Travel Guide can help them to find a local hospital. It also has a list of items it is useful to take when away from home and it has translations into French and German of the phrases which may be needed abroad. We have had positive feedback about the Guide but also need to receive negative feedback where the Guide is out of date. Updates can be sent to [info@cancerlt.org](mailto:info@cancerlt.org).

The Travel Guide can be downloaded from our website [www.cancerlt.org](http://www.cancerlt.org). To receive a printed copy of the 2017 Travel Guide please send a SAE with a 1st or 2nd class stamp on it, marking the outer envelope Travel Guide. Please ensure the envelope you send measures at least 6" by 8.5" (160mm by 220mm). Send your request to CLT, PO Box 618, Halifax, HX3

## Extract from Charity Annual Report

### Trustee Ros Oswald reports:

I often play for church services and after a recent baptism in our church found myself talking to one of the relatives of the newly christened baby. He had had a laryngectomy so I was keen to have a chat with him. As we were talking I told him about the Travel Guide and he was particularly interested as he is shortly moving to Spain. This got me thinking about where our members live.

When the Charity was started it was focused on Halifax where my father lived and where he had his operation. However, since then the word has spread about the Charity to a great many places throughout the UK. I know that Sydney would be very proud if he knew what a wide coverage we have. Having said that, he was always very ambitious and would probably be wondering why we did not cover the whole of Europe now! Part of the reason is the legal system and the fact that to some extent we have to restrict our activities to comply with Charity Commission rules. In any event I was very pleased to be told by my fellow Trustee Carole that we have members from as far north as the Hebrides, as far south as the Isle of Wight and Cornwall, as far west as Northern Ireland and as far east as Kent and Norfolk.

During 2017 I have been able to get to know some people who have had a laryngectomy and who live in the Swindon area near to my home. We enjoyed a very relaxing trip on the Kennet and Avon canal in a horse drawn barge. The lack of any sound from an engine made communication so much easier and the horse clearly enjoyed being able to sample the hedgerow as he towed us along.

Throughout the year the remaining activities of the Charity have continued including welcoming new members, providing financial support for lunches and outings, awarding grants to members in need, attending information events for patients and health professionals and creating and distributing newsletters to members. It is so encouraging to see the fundraising efforts which so many people carry out in support of the Charity. We also greatly appreciate the kind thoughts of family members who request donations in lieu of flowers at funerals when a much loved family member passes away.



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## Shout at Cancer

### Trustee Ros Oswald reports:

When I attended the Conference for Head and Neck Cancer Nurses in Birmingham I heard a lecture about a remarkable choir called Shout at Cancer. I love singing and help to run our local church choir. My father, our founder, also enjoyed singing although he preferred singing in the car as we drove along. His party trick was to sing You Are My Sunshine in Faroese as he learnt this during his time on the Faroe Islands during the second world war.

Once he had had a laryngectomy he did not return to singing – as far as I can remember. However, as I learnt at the Conference there is a choir called Shout at Cancer which is made up of people who have had a laryngectomy. It was set up in London and is run by a large team of people including speech therapists, doctors, professional singers and voice coaches. The first concert was on the 10th October 2015 in Christ College Chapel Cambridge. Dr Moors who spoke at the Conference was a singer with the Belgian Boys Choir and is able to combine medical and singing experience. The choir has performed at the Belgian Embassy in July 2016.

As a singer I know all about how valuable singing and breathing exercises can be to help with voice production. The choir members find these exercises particularly valuable after having a laryngectomy because they help to improve the range and quality of the voice. However, being in a choir brings so many other benefits including the camaraderie between the tutor and the other group members. If you would like to listen to the choir here are some links to them on Youtube <https://www.youtube.com/watch?v=usHaBMN3fvo> and <https://www.youtube.com/watch?v=CL5zEnKRdLI> . The website for Shout at Cancer is to be found at [www.shoutatcancer.org](http://www.shoutatcancer.org)

As well as singing, the choir also uses some techniques from beat boxing. I have to confess, this was a new musical technique to me but it is described as vocal percussion which involves mimicking drum machines. It is usually associated with Hip-hop music. Singing after a laryngectomy may not be for everyone but it is interesting to see what some people have found possible when finding their new voice.

## Data Protection and our Privacy Policy

We are sure you will have noticed that many organisations including charities are contacting you to talk about how they look after your information. The reason for this is that the rules about this have changed. We have always taken great care with the information we have about you because we take your privacy very seriously. However, to make sure we are in step with the legal rules as well we have prepared a Privacy Policy for the Cancer Laryngectomy Trust and put it on our website. If you would like a copy please let us know. Here are the main points.

- We only collect information from you so that we can support you
- We treat information about your health with extra care
- We do not sell your information to anyone else
- We do not share it with anyone else without your permission
- You have the right to request a copy of the information we do hold about you

If you have any questions please contact us.



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## Christmas Lunches

After the much appreciated Summer Lunches we are now busy planning Christmas Events.

The lunch in York will be held on Friday 30th November at Novotel. York YO10 4FD. If you would like to attend please contact Wendy Thompson, 10 Meadow Drive, Market Weighton, York, YO43 3QG Tel 01430 871561 email blwnt@outlook.com

The Blackpool lunch at the Imperial Hotel on Sunday 9th December is being arranged by Mrs Sandra Waddington, 76 Rutland Avenue, Poulton-le Fylde, FY6 7SA Tel 01253 899531 email waddington46@btinternet.com

The lunch in Halifax will be held on Wednesday 5th December at Windmill Court is being arranged by Carole Stainton contact at CLT, PO Box 618, Halifax, HX3 8WX email: info@cancerlt.org



**PROVOX<sup>®</sup> Luna<sup>®</sup>**

### Atos Medical wins the Red Dot Product Design Award for Provox Luna

Atos Medical is pleased to win the prestigious Red Dot Product Design 2018 Award for Provox Luna. The Red Dot Award is an international distinction for high quality design and innovation.



**reddot award 2018  
winner**



Provox Luna is a night-time solution that helps you sleep comfortably, soothe your skin and improve your lung health. Soft and smooth for night-time comfort.

#### Provox Luna HME and Adhesive

- Soft and smooth for night-time comfort
- Made of hydrogel to soothe and cool the skin
- Superior humidification compared to other HMEs
- Low breathing resistance for easy breathing at night
- Side openings to prevent occlusion while sleeping

 If you are interested in trying Provox Luna please email [sample@atosmedical.co.uk](mailto:sample@atosmedical.co.uk) alternatively call **0115 748 1897** or **0115 784 4301** and quote 'CLT LUNA'

As always we will contact your clinician to check the product is suitable for you.



**Atos**  
Atos Medical Your voice

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## Does your mouth feel dry or sticky? Don't ignore it!

### Wyvern Medical have a solution for you:

Xerostomia (Dry Mouth), is a common and often distressing complaint affecting millions of people in the UK, especially the elderly and those that have had treatment for head and neck/throat cancer.

The saliva in our mouths is created and delivered via a group of salivary glands, the major ones being the Parotid, Submandibular and Sublingual. These glands can be affected by a number of things including;

- Necessary radiation/chemotherapy
- A side-effect of medication for e.g. hypertension, heart conditions
- Diabetes and Rheumatoid arthritis

As a result, people (not just cancer survivors) can suffer from Xerostomia. Symptoms include: oral dryness, constant thirst, dry/sore mouth and throat, regular mouth ulcers. Xerostomia is often referred to as Dry Mouth, but actually this is a little misleading. Many people will indeed have a terrible sensation of oral dryness, whereas others' saliva will change and become thick and sticky.



Whatever the cause and symptoms, it's important not to ignore it. Not only is it uncomfortable, it can result in significant oral problems including: mouth infections (e.g. Candida), difficulties in eating/ swallowing/speaking, gum disease, tooth decay and sleeping problems.

Xerostomia (Dry Mouth) can really impact on a person's sense of well-being and quality of life. To help relieve the symptoms GP's often prescribe an oral spray. Saliveze is one such spray, that is known to be effective in relieving Dry Mouth. It is a low cost, effective spray available on prescription in the UK. It's mild taste and ease of use makes it a popular choice with Dry Mouth sufferers. For more information call Wyvern Medical on 01531 631105 or email [info@wyvernmedical.co.uk](mailto:info@wyvernmedical.co.uk)

## Professor Itzhak Brook



Professor Brook of Georgetown University School of Medicine in Washington DC writes to introduce his books:

*I am happy to inform you and your laryngectomy club that my books "The Laryngectomy Guide" and "My voice, a physician's personal experience with throat cancer" are available now for free download at the American Academy of Otolaryngology Head and Neck Surgery website: <http://www.entnet.org/HealthInformation/Laryngectomy.cfm> and <http://www.entnet.org/content/ebooks>*

*They are also available for free download at <http://dribrook.blogspot.com/>*

*Both are also available as a paperback and Kindle at Amazon.com. I hope that you will find these book useful and informative.*

*Sincerely, Itzhak Brook MD MSc*