



**CANCER  
LARYNGECTOMY  
TRUST**

Newsletter September 2017

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

Cover image by Autumn Mott on Unsplash

This newsletter is kindly sponsored by Countrywide Supplies and Atos Medical  
Charity Registration Number: 326653



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## Race Night 2017

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 20 of prizes of £10 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 18th 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 01430 871561 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 18th 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 trust. 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.**



**Hi Friends,**

As I sit writing this, I can see the roses in the garden and they seem very good this year. We have ones we got for our Golden Wedding Anniversary and one I received for my 80th birthday.

By the time you receive the newsletter we will have celebrated the wedding of Dr Nikki Oswald joint author of *Laryngectomy is Not a Tragedy*. At the moment I am busy getting my outfit ready. Earlier this year we welcomed our 2nd great grandson; blonde haired Joshua Albert, a brother for Riley.

A little bird has told me that the new edition of the Travel Guide should be ready later this year, fingers crossed. Now it's time again for Race Night so I look forward to receiving your entries.

Best Wishes,  
Wendy Thompson, Trustee

## Preston Support Group

Kim Winterton of the Preston & Chorley Districts Laryngectomy Support Group reports that a new banner for the club has been bought by Jim and Jill Brewster.

The photo was taken in the ENT Ward who held a raffle of Easter eggs and donated the money to the club, it was a nice surprise and very welcome.



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## Horse Drawn Barge Trip

On Monday the 18th September there is to be a trip on a horse drawn barge on the Kennet and Avon canal from Kintbury in Berkshire setting off at 2.30 pm . This is a follow up event for the Swindon area laryngectomees and their friends and relatives.

The trip has been made possible by the generosity of one of our donors who lives in Wiltshire. The trip will last two hours and will include afternoon tea. There are places available if anyone is interested. Please contact Ros Oswald, Trustee, if you would like to come. We are hoping for some good weather and great company.

Ros Oswald contact details: 17 Kandahar, Aldbourne, Wilts SN8 2EE.  
Email:the.oswalds@hotmail.co.uk Tel: 01672 540619

If you would like to know more about the trip you can visit the website of the barge company at [www.kennet-horse-boat.co.uk/horse-drawn-boat-trips](http://www.kennet-horse-boat.co.uk/horse-drawn-boat-trips)



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## Robin's Holiday Swim

After reading the item in our September 2016 newsletter Robin contacted Claire at the Aqua-ther service at the Royal Devon & Exeter NHS Foundation Trust where he received training to enable him to swim using the Aqua-ther.

Robin's wife reports:

*"We are enclosing a photo of Robin swimming in Tenerife, recently, using the Aqua-ther. We first heard about the swimming device in your laryngectomy letter and Robin was keen to follow it up."*

*He went to Exeter to be trained with it in January and thanks to Claire in Devon and Liz Nelson and Dawn Hayley at Castle Hill he was able to go swimming!"*

## British Association of Head & Neck Oncology Nurses

Trustee Ros Oswald reports on the recent conference:

On the 9th June 2017 I had a second opportunity to attend the Conference of the British Association of Head and Neck Oncology Nurses (BAHNON) in Birmingham. I had previously attended in 2015 and been very impressed with the obvious passion that the nurses attending the conference had for their work with cancer patients.

Once again the Cancer Laryngectomy Trust was invited to have a stand at BAHNON. A significant number of the talks were relevant to laryngectomees and it was a good opportunity to spread the word about the charity. There were friends of the charity there who had some very positive things to say about us. I was also able to make new contacts with Nurse Specialists who had not previously heard about our services.

The talks I found most interesting were those that related to quality of life for laryngectomees. We heard about the work being done by Shout at Cancer, a charity that has been very successful in setting up a choir for laryngectomees and which can be heard on their website [www.shoutatcancer.org](http://www.shoutatcancer.org). It was very moving to hear about the positive effect that being in the choir has had on some of its members.

Equally interesting was a talk about swimming again after a laryngectomy. Claire Barber is a Lead Specialist Nurse at the Royal Devon and Exeter NHS Foundation Trust. Claire and her small team have established a National Swimming Centre for neck-breathing patients. The talk was accompanied by photos and videos that enabled us to see just how much it means to someone who thought that swimming would no longer be possible. I don't think Sydney would have been interested in swimming after his operation but for some people it is clearly a very enjoyable pastime.

Having spent a considerable amount of time updating the Travel Guide I was able to check the information in the guide with a number of people there. It was very encouraging to see how much more accurate the guide has become. I also met Chris Harris, a Dispensing Relationship Manager from Fittleworths which is supporting the printing of the guide. We were able to agree some of the wording to be included in the guide in relation to the company.

I was also able to catch up with Malcolm Babb from NALC who do such good work in supporting Laryngectomees.

The day was a very busy one and it was so encouraging to meet so many health professionals who are dedicated to providing and improving the care for laryngectomees. It was obvious that the nurses are very clear about how important it is to provide emotional as well as physical support for both patients and their families. This is something which was so important to Sydney in setting up the Cancer Laryngectomy Trust and working with BAHNON is an ideal way to make sure we are all working together when our aims are so similar.

## Christmas Lunches

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

**The lunch in York will be held on Friday 1st December.** 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 lunch in Blackpool will be held at the Imperial Hotel on Sunday 3rd December.** If you would like to attend please contact Sandra Waddington: 76 Rutland Avenue, Poulton-le Fylde, FY6 7SA Tel: 01253 899531 Email: waddington46@btinternet.com

**The lunch in Halifax will be held at Windmill Court on Wednesday 6th December.** If you would like to attend please contact Carole Stainton: CLT, PO Box 618, Halifax, HX3 8WX Email: info@cancerlt.org



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## Countrywide Supplies Community Events

Our Newsletter sponsor Countrywide Supplies is hosting a series of free community events around the UK in partnership with its sister company Atos Medical.

The aim of these small, friendly events is to inform and educate larygectomees and their caregivers about topics and themes that may be helpful.

Previous themes include *Feels Like Summer*, where attendees received a complementary recipe book and tips and ideas that could potentially help to improve taste and smell. *Staying Active* also featured on the event schedule over the summer. At this event attendees received a complementary pedometer to help them track their daily steps, and discussed how they might prepare for an active day.

Upcoming themes include *Better Sleep* which focuses on ideas for getting quality rest and an event around the topic of travelling as a larygectomee.



A photo from a recent Atos Medical and Countrywide Supplies community event in Blackpool

These community events are free to attend for all who wish to. To find out where your next local event is call the Countrywide Supplies events team directly on the numbers below.

**For events in the south:**  
Call Rosie Harbor on 0115 784 5652

**For events in the north:**  
Call Phoebe Benta on 0115 784 1897

## Travel Guide 2017

Trustee Ros Oswald has been working hard to update the Travel Guide and reports on progress:

I am often asked what the Cancer Laryngectomy Trust does to help people who have had a laryngectomy. One of the ways in which we help is to produce a Travel Guide which provides information 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 that are useful to take when away from home, and it has translations into French and German of the phrases which may be needed abroad. The Travel Guide was the brainchild of Paul Cantlie who produced the first edition. Sadly, Paul has now passed away but we did not want the guide to come to an end.

The only problem with a guide such as this is that it is in constant need of updating. The NHS is in a state of change, even to the point of knocking down a hospital and building a new one. Therefore, as Trustees we decided that the guide needed a thorough update. This included putting postcodes into all the addresses and extending the list of languages into which the useful phrases are translated. This has proved to be a mammoth task and a very informative one.

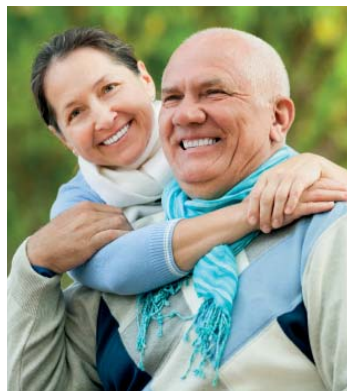
In principle it sounds quite simple to ring each hospital to check their details. However, when you ring a hospital you are met with a bewildering variety of responses. These have ranged from “number unobtainable” through “please dial the extension you want”, when you don’t know the extension in the first place to (rarely ) “Hello how can I help , I am the specialist nurse you need”. I often had to leave a message asking for a call back but rarely received one. I began to realise how difficult it is to find help if you are not in your own area. We have decided to publish the updated guide even though we have not been able to make contact with every single hospital, but by putting guide onto the website we can keep the updating process going on a rolling basis.

We have had positive feedback about the guide but also need to receive constructive comments where the guide is out of date. Our hope is that the Travel Guide will continue to help and give confidence to laryngectomees as Paul intended.

**We hope to have the new edition ready within the next month or so. To receive a copy of the 2017 Travel Guide please send a SAE marking the outer envelope Travel Guide. Send your request to CLT, PO Box 618, Halifax, HX3 8WX.**

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