

TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

Race Night 2016

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 20th 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 20th 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 £8300 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, summer seems to have come at last, we hope you are enjoying it.

We seem to have had a very busy few months starting with a trip to Athens with Sarah our daughter and Emma our grand-daughter to visit our sister Janet's grave. Then a trip to Germany for a party to celebrate our penfriend's 60th Birthday Party which included a fire-eater and belly-dancer.

We have met members and carers at their meetings in York which we find very interesting and then the Summer Lunch at Bridlington, as usual the sun managed to shine.

To end our activities for the moment I celebrated my 80th birthday with a lunch for all our family; 14 of us including partners of grandchildren who put me before work.

Next thing is Race Night, I look forward to receiving all your entries!

Best Wishes

**Wendy Thompson
Trustee**

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Dawn's Rome Marathon run for CLT

Dawn reports on her run:

Just to let you know that I completed the Rome Marathon on Sunday 10 April 2016 through grit and determination. The atmosphere was amazing, the crowds super, bands playing and lots of noise. Scenery and route stunning.

It was however very hot, hilly and miles and miles of cobbles. I stuck with the pacer until mile 18 then hobbled to the finish. I cannot describe the effort to finish. I gave my dad my medal as he is in so much pain that his effort to get here exceeded mine and all I could think was if he could get here to Rome to watch me run that I could finish as my pain was temporary.

We are now enjoying a relaxing break in Rome.

Best wishes

Dawn

Dawn raised a magnificent total of £1200, including Gift Aid. We are very sorry to report that Dawn's laryngectomee father sadly died in July.



Swimming for Neck-Breathers

The Aquather service at the Royal Devon & Exeter NHS Foundation Trust has now been signed off at Trust level and has been given the green light to go.

It is open to all patients in the UK and is designed to reintroduce patients who breathe through a tracheostoma to safely re-enter the water for leisure or therapeutic intent.

The development of this service has taken 12 months longer than anticipated due to the level of strategic planning needed to ensure a safe and robust service however a number of patients are already practicing self- insertion of their tracheostomy tubes in preparation for their training.

FORCE Cancer Support has been instrumental in driving this initiative forward and has fully funded this exciting project on a 12-month pilot basis. Macmillan Cancer Support has already issued a number of generous grants to patients who would otherwise not be able to afford the snorkel device.

The National Association of Laryngectomy Clubs (NALC) which acts as an umbrella organisation for all laryngectomy clubs throughout the UK has kindly endorsed this service, and following discussions with Club President Malcolm Babb, will act as a source of referral for any enquiries they receive.

Patients must be over 18 years of age and have capacity and the ability to communicate effectively. For more information please contact NALC or The Head and Neck CNS Team on 01392 402 215 or visit the Royal Devon and Exeter NHS Foundation Trust website – A to Z Services - Head and Neck Cancer Services – Aquather.

Peter Helps Others

Peter Holloway chairs the Glan Clwyd Laryngectomy Club in North Wales, which counsels and supports those facing treatment for cancer of the larynx since having treatment himself at Glan Clwyd hospital.

Specialist nurses and surgeons now invite him to share his experiences with patients who are about to undergo the same complex operation and help to ease their worries.

He says: *There's no doubt it's a frightening time and people get very worried about what is going to happen. I go in, if a patient wants me to, and try and talk them through it so they can see it's not all doom and gloom.*

Peter, who also plays the drums with the Llandudno Swing Band, took over as chair of the Laryngectomy Club eight years ago at a time when it only had four members, and has since seen membership grow to 24.

He says: *We meet every six weeks at the Faenol Fawr Hotel, right next door to Glan Clwyd hospital. We try to offer support and it's a great way for people who have had a laryngectomy to get together, with or without their partners, wives and husbands. We have guest speakers come in but basically it's a way to socialise, sympathise and offer support.*

Liz Thomas, a Ysbyty Glan Clwyd speech and language therapist, also comes along to the Laryngectomy Club meetings and is always on hand to offer help and support.



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16 Cancers/ Quit 16 TV advertisements

In February we were contacted by one of our members who had seen the TV advertisements which formed part of the 16 Cancers /Quit 16 campaign. The advertisements which were only shown in the North East were intended to discourage people from taking up smoking or to stop people starting to smoke. However, the way in which the advertisements showed the stoma of a person who had had a laryngectomy had caused distress. In addition the implication that all people who have had a laryngectomy had been smokers was also distressing.

As a result, on behalf of the trustees, I contacted Public Health England to express these concerns. We received a reply from Fresh which is the body that had produced the advertisements and which is dedicated to achieving a smoke free North East. Its website is at www.freshne.com if you would like to find out more.

Their response was as follows. The advert was developed in Australia and adapted to run in the north east. Fresh said that they had worked with people who had had a laryngectomy who had given their full backing and support. Fresh acknowledged that the adverts were not always pleasant viewing but felt that campaigns such as this are very important in reducing the number of smokers and therefore reducing the number of cancer deaths which they put at 38,000 in England.

Fresh acknowledged that not all cancers are caused by smoking but stated that their advertisement did not say that that was the case. They also said that the people they worked with who had had a laryngectomy were keen to share their stories visually.

Of course, these replies do nothing to help our members who do find the advertisement distressing. What has been agreed is that the charity will be notified when the advertisements are to appear so that we can include information on our website to notify our members. Unfortunately it is not possible for us to write to every member individually. If you have any thoughts or views about the advertisements please let us know. We are happy to pass on any concerns you may have.

Extract from Trustees Annual Report by Ros Oswald

I was reading through the list of activities for 2015 when one fund raising event caught my eye. This was the dressage competition organised by Rose and Jon Coley at Ladysmith Equestrian Centre in Wiltshire. As Trustees, we are so grateful for the efforts that are made by many different people to raise funds for the Charity. This event was particularly special because it involved horses and it enabled more people to find out about the Charity and how it is able to help.

Horses were a large part of our founder Sydney's life. The reason that Race Night is so important to the Charity is that it combines two of his big interests, horse racing and raising funds. After Sydney's laryngectomy he needed to find a way forward that made sense to him. His voice had always been so important to him and he needed to find out for himself how to live the new life that the surgeons had given him. I was at Haydock Park races with him and his wife, Lucy, when a horse he had bred, Ziparib, was running. It was not expected to win although it was fit and looked well. As the race progressed it became obvious that in fact Ziparib was going to be the first past the post. Lucy and I were almost in tears as we knew how much this meant to Sydney. He had arrived at the race course looking tired and weak. However, as soon as Ziparib had finished the race he ran out onto the course to lead him into the winner's enclosure. (See page 23 of Laryngectomy is not a tragedy for the photo of that important event). From that day on he did not look back. He made the decision to set up the Charity and dedicated the rest of his life to raising funds.

When Jon and Rose said that they were willing to hold a dressage competition to raise funds, this brought back so many memories of that day at Haydock. The horses at Ladysmith had been groomed to perfection and the riders had clearly spent many hours learning their tests and working on the movements they had to perform. Sydney's grand-daughters Elly and Victoria were the judges and his great grand-daughter Lucy was also in attendance in her pushchair. I am sure Sydney would have heartily approved of such an entertaining fund raising event.

So, if you can walk, run, swim, ride, cycle, bake, make tea and coffee, sew or do anything else you enjoy, there is always a way to raise essential funds for the Charity and have fun in the process.

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Summer Lunches and Outings

Members enjoying various outings supported by the charity.



web site: www.cancerlt.org
email: info@cancerlt.org



**CANCER
LARYNGECTOMEE
TRUST**

**Cancer Laryngectomy Trust
National Association of Neck Breathers
PO Box 618
HALIFAX HX3 8WX
Telephone/Fax 01422 205522**

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