

TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

**Dear Friends**

**25<sup>th</sup> Anniversary Race Night**

We are very proud that the charity is celebrating the 25<sup>th</sup> Anniversary of its creation by Sydney Norgate and hope that you will support the 25<sup>th</sup> Race Night and Raffle. 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. We draw out the winners and a prize is sent to the winner of each race. We also have the raffle tickets at 20p each or £1 per book of 5 with cash prizes. 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 22nd 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. 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 to the office by 22nd October.

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 £5400 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.



Winners Race Night 2009

**Message from Trustee Wendy Thompson**

Dear Friends

Once again it has come round to Race Night and Raffle. This year it's the 25<sup>th</sup> event, where have all the years gone! When I wrote last time I promised to tell you all about our trip to Turkey alas the volcano put a stop to it. All wasn't lost though as we had a very enjoyable weekend in Harlow where Bill was born meeting up with our Best Man and his wife. We also had an enjoyable trip to stay with youngest sister Ros to take part in their Civil War themed village fete. As Bill is a direct descendent of Oliver Cromwell we dressed appropriately for the event which included a banquet and a Black Adder sketch with brother-in-law as Baldrick. There have recently been two four-legged additions to the family Ros's cat Max and Carole's puppy Bracken, sadly both are replacing pets lost to cancer.

We have enjoyed meeting some of you at Summer Lunches and are planning Christmas Events too. If any group is planning a Christmas Lunch we will be pleased to consider a Grant Request to support the event.

Good Luck for Race Night

**Wendy Thompson**

### Safe Journey Card & Liberty Wallets

A number of bus companies have introduced Safe Journey Cards to help disabled passengers to communicate any problems they might have to the driver. The card produced by First has a number of pre-printed messages such as Please be patient I have difficulty speaking to show when getting onto the bus.

In East Yorkshire an orange Liberty Wallet can similarly be used to alert the driver that the passenger might have problems.

Members might wish to check whether their local bus companies offer similar services.

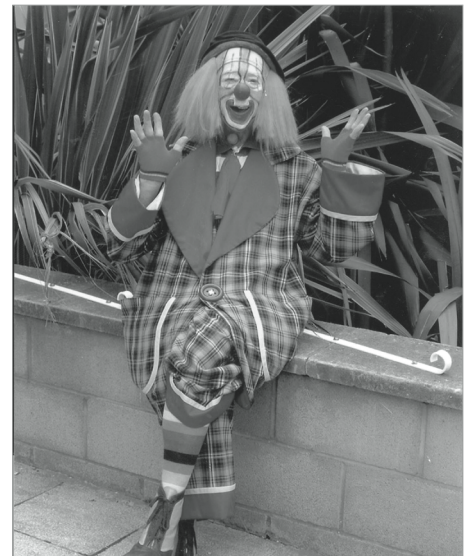


### Texting in Emergency Situations

A texting service for people with speech or hearing difficulties to use in emergency situations is currently on an extended trial. To be able to make use of the service you must first register your mobile phone number by either going on-line to [www.emergencysms.org.uk](http://www.emergencysms.org.uk) or by texting the word 'register' to 999 then following the instructions you receive. The service must only be used by people who can't make voice calls. If an emergency occurs once you have registered you can then send a message to 999 stating what the problem is and you will receive a reply within 2 minutes.

### Farewell to Buddi

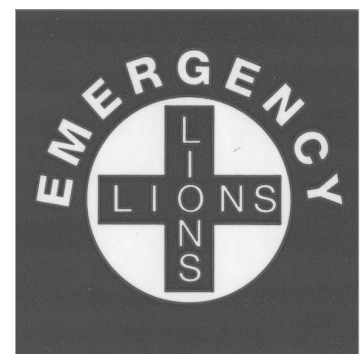
We were very sorry to hear of the death of our good friend Bernard Beetles also known as Buddi the Clown. Bernard worked tirelessly to help other laryngectomees in his area of Lancashire. He decided to adopt the clown persona so that he could go into schools to show off his juggling skills and to talk to the pupils about the dangers of smoking at the same time. We will all miss his interesting anecdotes of his working life in the entertainment business.



Bernard Beetles - Buddi the Clown

### Lions Message in a Bottle

A voluntary scheme sponsored by the Lions Club offers the facility to record information such as medication and contact addresses and store the information in a container which will be recognised by the emergency services. The containers are available from Rowlands Pharmacy nationwide. A leaflet MD105 explains the scheme and provides space to record personal details, medication etc. The information is then stored in the fridge so it can be found by the emergency services personnel.



## Welcome to Jamie Bravedart Harvey

We are pleased to welcome a new member who writes:

*"I was a full time professional dart player for over 25 years. My pro friends include Eric Bristow, John Lowe, Jocky Wilson and many more. I traveled all over the world with them playing darts. It was a hard life, drinking and smoking and passive smoking in clubs and pubs all over the world. Hence my throat cancer. . Now I go to the hospital to talk and put at ease patients who have or are about to have the same operation as me. I feel fantastic after talking to them myself that I may have helped someone who is in the position I was in. It feels good and it also keeps me in a positive mood to fight this terrible cancer."*

**Jamie Bravedart Harvey**



## Swallow Laryngectomee Club Outing

Philip Wardle, Chairman of the Swallow Laryngectomee Club from South Wales, wrote to thank the trustees for the grant to his group which had supported their outing with the following:

*"A pleasant day was enjoyed by all, following collection of members from their distant abodes we sat to an excellent meal of two hours relaxation, and moved on to the guided tour and history of Craig Y Nos Castle where past owners have each added to the building."*

*A first rate opportunity for our newer laryngectomees to relax, engage in speech, and to re-enter the community atmosphere."*

**Many thanks,**

**Phil**



Swallow Laryngectomee Club outing

## News from The North.

*"Hi this is Bob, the secretary of T.A.L.K, a social group of laryngectomees based mainly in Newcastle Upon Tyne. We have over sixty members and we meet on the third Tuesday of each month 12 noon at The Royal British Leigon Club West Jesmond, our meetings are always well attended, we have a buffet, a raffle and usually a guest speaker."*

*Whenever we get the chance we like to get ourselves out for the day, and on the 14th July we took a coach to Berwick upon Tweed, the only town in England to have a football team in the Scottish Premier League. We arrived just before lunch, the ladies did the shops and the market, and the blokes did the bookies and the bars, we all met up for a fish, chips and mushy peas lunch swilled down with hot tea, and then did a spot of site seeing taking in the famous army museum, the city walls and the three bridges. After a busy few hours site-seeing we all met up for a well earned drink and the landlord of the bar that we were in kindly took this photograph. The photo shows from left to right, Ron, Tony, David, yours truly Bob, Dot wife of John, Nurse Jerry, Tony's wife Jean and finally John. Nurse Jerry really is one in a million, she's worked at the Freeman Hospital for well over 20 yrs mainly with laryngectomees, and even did a stint in speech therapy. On the day of our trip she should have been at the university to celebrate her own graduation, but instead she choose to spend it with us, and get a right ear bashing from Ron, think she must know his life story now."*

*Well that's just a little bit about us, should you find yourself in Newcastle on the third Tuesday of the month, do come along and join us, we'd love to meet you. There is always enough food for a few new friends, which brings me onto the next thing, which is a big, big thank you to The Cancer Laryngectomee Trust for donating £250 towards a Christmas meal for our members".....**Bob Carey.***



Talk Club in Berwick

## Extract from Queen's Medical Magazine

The following article was written by Nikki Oswald, one of Sydney Norgate's grand-daughters who is studying medicine at Birmingham University.

### What you need to know about Laryngectomy

#### Why is it performed?

Laryngectomy is a curative therapy in cases a laryngeal cancer, normally a squamous cell carcinoma, and carries a good prognosis. The incidence of this kind of cancer was approximately 4 per 100,000 population in 2004 making it one of the most common of the head and neck cancers. Incidence is highest after 60 years of age, higher for men and patients presenting with this are invariably smokers.

#### What does it involve?

The surgery alters the anatomy of the upper respiratory tract to allow the larynx to be removed. The trachea is connected to the anterior of the neck and opens directly into the surrounding air, the respiratory opening into the pharynx is closed and the pharynx hence leads only to the oesophagus.

#### What are the consequences?

Normal speech is no longer possible for the patient and this has an immense impact on lifestyle following surgery. The patient must learn how to speak in a new way from scratch with a lot of determination and rehabilitation. Good communication can be restored with the use of pharyngeal speech, using a process similar to burping. Various electronic devices can create vibration to aid production of speech if the person has limited success with pharyngeal speech and a small amplifier can be used if the voice they produce on their own is too soft.

Research has shown support following surgery dictates quality of life far more than the quality of the surgery itself. This being the case it is important that patients have good support from the healthcare team, their social network and dedicated support groups.

The function of the nasal cavity is lost so cold, unfiltered air goes into the trachea making infection more likely. Swallowing is often more difficult so adjusting diet may be necessary.

Stoma care is very important and care must be taken in daily life to prevent blocking the stoma (e.g. Swimming requires a special cover).

#### Why should I care?

In various specialities awareness of the relevant conditions is important. However this knowledge is important for everyone because it can prevent clinicians killing people. Performing conventional CPR on a laryngectomee can prove fatal as air must be given through the neck stoma rather than the mouth. Quick observation of the neck can reveal if the casualty has a stoma and they will most likely be carrying a warning card too.

**Laryngectomy** - surgical procedure involving removal of the larynx.

**Laryngectomee** - person who has had a laryngectomy.

#### Sources

The Cancer Laryngectomee Trust  
Cancer Research UK  
The American Cancer Society  
Macmillan Cancer Relief

web site: [www.cancerlt.org](http://www.cancerlt.org)  
email: [info@cancerlt.org](mailto:info@cancerlt.org)



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