



TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

Dear Friends

What a difference a year can make to the weather, Carole had daffodils out of her garden in flower on her dining table on Christmas Day. However we have suffered with the winds this year and hope you have all managed to survive them as I know they aren't very kind to Larrys.

Many thanks to everyone who supported Race Night which once again was a great success raising over £2000 for the charity. Bill and I worked hard to make sure all the race and raffle prizes and results sheets were sent out before Christmas. It was good to be able to present some of the winners trophies at our Christmas Lunches.

At the Patient Focus Group Meeting held at Queen's Medical Centre in December I spoke about the history and current work of the charity and was pleased to meet up with many Larrys, some having been members for many years. It was good to get feedback about how supportive the trust is both before and after surgery.

We had an anxious time in November when our sister and fellow Trustee, Ros Oswald, had major heart surgery. We are very pleased to say that she is making excellent progress.

Holiday brochures have been dropping through the letterbox, so far we haven't booked but maybe a trip on Eurostar after our twinning trip to Germany in June. We are looking forward to a treat of a mini break in York, for my birthday in July, arranged by our daughter Sarah. We can be tourists for once looking at sites we don't usually visit. At least we should be able to find the places without a map!

Best Wishes,

Wendy Thompson, Trustee



Caption Prize Winners receive their Trophies



Summer Lunch in Blackpool

After the success of our Christmas Lunch we are holding our Summer Lunch at The Savoy Hotel, Queens Promenade, Blackpool FY2 9SJ Tel. 01253 352561 on Sunday 17th June 2012, 12.00pm for 1.00pm

If you would like to attend the lunch in Blackpool please contact Malcolm Rothwell, 23 Dorset Road, Atherton, Manchester, M46 9PP Tel 01942 892403.

If anyone would like to stay overnight at the hotel special terms for bed and breakfast for one night of £25 per person sharing a double room or £30 for single occupancy will apply.



Swallow Laryngectomee Club Outing

Philip Wardle ,Chairman of the Swallow Club, reports as follows:

For our club outing in July we visited Tretower Court and Castle. The castle is of historic interest, originally built in 1121 and added to by the construction of the Tower and extensions to the Castle up to about 1240. At about 1450 a new and more fashionable residence was built within the shadow of the Castle which became known as



Tretower Court. It has no defensive qualities but with further accommodation became a 'Court of Royal Style' famous for its fine wines and with generous kitchens.

A lunch meal was held at the Vine Tree Inn, Llangatock, followed by a guided tour around the Castle and Court giving time to relax in the medieval gardens to end the visit.

We thank you for the grant which enabled this very enjoyable event to take place.

Swallow Club Members at Tretower Castle

Kim's Success at Crufts

We thought you might like to share Kim Winterton's approach to coping as a Larry;

A funny thing happened on the way to the theatre, the operating theatre that is, I half sat up, the other half was full of drugs, and I exclaimed "*how am I going to breathe*" I was still asking the question when wheeled into the theatre, the rational becomes the irrational. The next thing I remember is a nurse saying "*we are cooking on gas*" gas I've got electric at home - what she meant was I was ready to go back to the ward. Time stood still for a few days and I made attempts at oesophageal speech which worked to a point, I did have a valve in place. My lovely consultant was going on holiday and I said "*are you taking your Speedos*" he could not understand so I wrote it down, he could not read my writing, you should see his!!!

I decided that I would deal with all this with humour which sometimes comes across as "*full of herself*" and dog showing which I did before my op.



Kim at Crufts

I have had some very funny moments like coughing my Lary tube out my dog somehow caught it and looked as though he had a dummy in his mouth, and on my hands and knees in the middle of the night looking for the expelled tube when I coughed, and having a tube landing in my soup!!!!

I wear a foam cover and boy don't people stare, or is it my hair, a man walked into a pillar through staring how I stopped myself laughing I don't know, also the lady at the supermarket checkout who raised her voice up an octave and spoke as though I had a mental problem too, no comments please.

I qualified Zac my Hungarian Vizsla for Crufts 2011 and was overjoyed to get a 2nd in my class, I stand him and my husband runs him, lovely day.

I have had many highs and a lot of lows but sitting at home feeling sorry for yourself solves nothing, even now after being diagnosed with another cancer and having chemo, think of the plus things I cant get breathalysed, sing, snore, choke, blow up balloons, down side wait for soup to cool takes ages doesn't it ?

My valve had to be taken out and I speak oesophageal speech and everyone says it is the best they have ever heard, the final accolade came a few weeks ago when I got told off for shouting. Result.



Dental Treatment for Laryngectomees

A cautionary tale from Geoffrey Read:

I use Denplan (a private treatment and insurance plan) so I was reasonably dental-fit prior to having my laryngectomy in January 2009. However, I've been needing more and more dental treatment since my chemo and radio therapy sessions as my teeth have begun to deteriorate.

The radio therapy also damaged the tissue in my oesophagus causing it to constrict. I frequently have to be admitted to undergo a procedure under general anaesthetic to have it dilated... a very delicate procedure, whilst trying not to tear the membrane or causing further damage in any way! I've received 15 or so dilations since my laryngectomy.

A day after my most recent operation, part of the crown of one of my front teeth fell away. I immediately reported to my dentist who agreed with me that it was probably damaged during the dilation procedure as it would not just have come away on its own accord! So... I completed the necessary claim application form and submitted it to Denplan whilst feeling rather smug about how wise I was to have taken out dental insurance as part of my Denplan! I've just received the reply from Denplan and it somewhat knocked the smugness from my face! Their Clinical Support Advisor wrote:

May I advise that dental injury resulting from the administering of required general anaesthesia as part of an elective surgical procedure is a direct exclusion. Our legal department has advised us that it is the duty of care for the hospital to make good any damage / injury sustained whilst the patient is in their care. We are therefore unable to accept the claim under the terms and conditions of the Supplementary Insurance Policy.

So should I approach the hospital and ask them to make good? We all know that before undergoing any surgical procedure one has to sign a Consent Form. We also know that these forms are not simply to give one's consent... one is also signing to say they accept that any damage done will not be the fault of the hospital nor the medical staff. Always a water tight disclaimer!

Fair enough... it seems I will have to pay out of my own pocket for the damage done to my teeth. But this whole affair does leave a nasty taste in my mouth!

Runners Needed for The British 10K London Run 8 July 2012

As London builds up towards the 2012 Olympic Games we will have a team of runners taking part in the British 10K London Run on Sunday 8 July. We are inviting runners to take part in the 2012 race on our behalf. We have purchased 12 places for the race which starts at 9.35am at Hyde Park Corner with the route travelling along Piccadilly, Pall Mall, along the Embankment towards Tower Bridge back to Westminster Bridge and into Whitehall for the finish. This year we will have Chip Timing and an Official Race Photo for each team member.

Runners must be at least 15 years old and be capable of completing the race in under 2 hours.

Individual runners must complete the registration form (available from CLT, PO Box 618, Halifax HX3 8WX or info@cancerlt.org) which contains our Charity Race Ref No P937 and return the form to CLT. These entries will then be entered on-line via the race website. We have had to purchase the Platinum Debentures for our runners but we do not plan to charge people to run for us. What we would hope is that each member of the team will attempt to generate at least £50 sponsorship for the charity. A sponsorship form has been prepared which you might wish to make use of or alternatively you can prepare your own version. We have permission to use the race logo. Please encourage anyone who is eligible (i.e. UK tax payer) to tick the Gift Aid box as this increases the value of their donation at no cost to them.

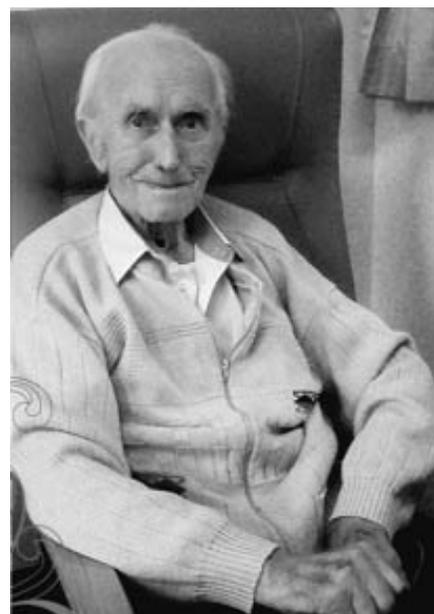
For more information see the CLT website www.cancerlt.org or www.thebritish10klondon.co.uk



Tom Connolly

We were very sorry to hear of the passing of a very long-standing member Tom Connolly of South Shields. With their permission we would like to share with you part of the letter we received from his family who kindly asked for donations in Memory of Tom to the charity:

Tom had been a laryngectomee for 25 years after he had his operation done by Mr McKay in Sunderland. He could not use any aids to make his voice but we all knew how to understand him. He enjoyed a good life, going to meet his pals at the club and having a few pints. He was dearly loved by all his loving family, he will be sorely missed.



Members Trips and Lunches

Fifteen members of the Windpipers club enjoyed a super day out in the Lake District last summer. They travelled by coach to Haverthwaite, steam train to Lakeside and then embarked on a steamer which sailed to Bowness-on-Windermere. During the boat trip the group enjoyed a rendition of Wordsworth Daffodils from one of the members 'a young gentleman of 80 years'. A meal in a Bowness restaurant followed by delicious ice cream rounded off the day.



Ann Muir reports that the Speak Easy group enjoyed their New Year Lunch and she even taught me a new word in her e-mail 'The lunch was really nice and everyone enjoyed the opportunity to sit and bleather and relax in good company'.

We are very happy to consider grant requests from groups of members to assist with the funding for trips or lunches such as these.

Windpipers at Bowness Pier

Speech Methods Questionnaire

Thank you very much indeed to all of you who returned completed questionnaires on the speech methods you use. It was very interesting to us to read about your experiences. It was also good to read the lovely comments about the help some of you had received from our Founder Sydney Norgate and his wife Lucy.

Nikki Oswald is now busy analysing them to inform her work on the new chapter for the book Laryngectomy is not a Tragedy. She qualified this year as a Doctor having studied at Birmingham University and has a particular interest in ENT surgery. Her work will be supervised by Mr Paul Pracy who is an ENT Consultant at Good Hope Hospital and Queen Elizabeth Hospital in Birmingham.

web site: www.cancerlt.org
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**CANCER
LARYNGECTOMEE
TRUST**

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