



TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

Dear Friends

As I am writing this I am watching the many different kinds of birds on our bird table including a jackdaw and a magpie! We don't seem to have any squirrels around here. I remember them in the garden at Halifax fed by my mother, Lucy. We had a wonderful time in Greece, seeing our sister's new house near Athens and also enjoying a trip up to a typical Greek village where we walked through very green woods and saw many different wild flowers. However my husband says we can't go away again in May as there is so much to do in the garden in particular planting vegetables, sprouts for Christmas being very important. We all have happy memories of our father, Sydney, preparing his seed potatoes and bringing in fresh vegetables from the garden.

We have been to two Summer Lunches. One on the West Coast and the other on the East and met many members and their very important carers. It is very nice to see you and then be able to put names to faces. When we got back to York from Blackpool, Ascot Races was just coming to a close and the Railway station was teeming with ladies in their beautiful hats and the men in their top hats, what a lovely site. Talking of the races reminds me to invite you all to join us in our Race Night fund raising event. Hoping you have all managed to enjoy some summer weather.

Best Wishes from all the Trustees,

Regards, Wendy Thompson

### **Mini Break in the Lake District**

Once again we are very grateful to the proprietors, one of whom is a laryngectomee, of The Sawrey Hotel who have donated the first prize for our raffle as part of Race Night 2005. The prize consists of two nights dinner, bed and breakfast for two people to be taken some time between 3rd November 2005 and 6th April 2006, excluding Christmas and New Year. In addition to this splendid first prize there will be dozens of smaller prizes too as usual.

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. 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 31st 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 31st October.



*The Sawrey Hotel, Lake District*

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 £1200 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.**

## Bratton Silver Band Concert

Trustee Rosalind Oswald reports on this event:

After a rather difficult period of illness over 18 months involving three major operations I was ready for some relaxation. I was also delighted to be able to attend an event connected with the Charity as I am the Southern outpost as far as the trustees are concerned. The concert was in Devizes which is a market town about 20 miles from my home and as luck would have it one of my friends from church used to play with the Bratton Band 20 years ago. He was very keen to renew his acquaintance with Les who is the laryngectomee who plays in the Band. So my husband Chris, our friend Ray and I set off hoping for an relaxing evening.

As soon as we arrived we were welcomed and I was introduced to Les. I was quite astounded at how friendly and welcoming he was inviting me into the Band room to see him warm up on his Baritone Horn. I was fascinated to see how he could perform such a difficult feat but he was very much in control of the instrument and produced a lovely warm sound.

I took my seat in time for the concert and we were royally entertained. The programme was interesting and varied – from the Beatles to Faure with plenty in between. The soloist was Sheona White who won the BBC Radio 2 musician of the Year in 1996 and played on the world acclaimed CD Perfect Day. She and the entire Band communicated their love of their instruments so well and gave us plenty to applaud. There was also another laryngectomee who had come all the way from Cornwall.

At the interval we were able to see Les again and he recognised our friend Ray as soon as he saw him. They had obviously had a very entertaining time 20 years ago but declined to fill me in on all the details! The second half of the concert was equally enjoyable and for me Hymn to the Fallen which comes from the film Saving Private Ryan was particularly beautiful.

We were told about a CD the Band is shortly to record and I ordered my copy. My daughters pony Toby does dressage to music and particularly likes band music as the beat is easy for him to pick out. I am looking forward to seeing Toby strut his stuff to Les on his Baritone horn playing A Hard Day's Night!



*The Bratton Silver Band in action*



*Les Wood and Rosalind Oswald at the concert*

All too soon the concert was over and we took our farewells having made some new friends. It was a marvellous evening and we are very grateful to the Band for thinking of the Charity.

I can thoroughly recommend the CD which can be ordered for £7 from Lisa Hill Band Secretary at 49 Wiltshire Way Westbury Wiltshire BA13 3XD or e-mail [secretary@brattonsilverband.co.uk](mailto:secretary@brattonsilverband.co.uk)

As long as people like Les are around the world will be a happier and a livelier place.

## A better person for having had cancer?

Councillor Mark Harris, Leader of Leeds City Council writes:



This may seem a bizarre way to begin what I have to say, but I often believe that I am a better person for having had cancer. Perhaps if things had worked out differently I would not have such a laid back attitude. Part of that is the way in which life can conspire

for and against you, almost totally beyond your control.

I was 33 when I was diagnosed with cancer in April 1989. It was not meant to be cancer, but during a routine operation for a thyroid goitre the true position jumped out at us. 19 days later, another two operations on, three stays in ICU and an initial terminal prognosis I was a laryngectomee. I was then and now grateful for the awful speed with which it all happened. I had no time to think about anything except surviving.

As it transpired I had thyroid cancer. Rare in men, not seen at Jimmy's for a generation so at first they did not know what they were looking at. It had spread up to my brain and down across my vocal chords. Too late for any form of chemo or radio therapy, it was chop it out or not at all. My vocal chords really went almost as a side line in the third operation.

One of the great ironies was I had stopped smoking 5 years earlier because I was so scared of getting cancer. Nobody has been able to tell me exactly where it did come from, but the best bet was Chernobyl. Like the sheep in N Yorks I must have been outside when the radio active rain fell. Certainly after me there was a cluster of other thyroid cancers so it makes sense.

So at the time all I could think of was surviving. My daughter was one year old and I had to see her grow up. Now I also had to learn to talk again so we did it together. My job was and is talking. A Sales Director by day and a Leeds City Councillor by night, who has ever heard of either not being able to talk. I use the word advisedly, but it was nothing short of miraculous the way I began to speak oesophageally and the speed with which I began to recover.

It would be easy to say I have never looked back and perhaps to some extent that is the case. But in reality, there were some awful ups and downs with moments of mind numbing doubt and fear.

But these are the things I believe I have learned from it all.

Firstly although I received first class treatment at Jimmy's and Cookridge ( for whom I have now run ten full marathons raising money) and I am devoted to both for saving me against all the odds, I think that had I taken the advice given by many doctors and nurses my recovery would have been much slower and perhaps less complete. As in all things in life, I believe you must aim high otherwise you will always underachieve. The trick of course is then dealing with not succeeding if that is what happens. A few people encouraged me to shoot for the stars but most advised me I should lead a quiet sedentary life now that I was disabled.

Secondly, deal with the "does he take sugar" syndrome immediately before everyone gets into a rut. After a few days of having people shout at me to make me understand, write answers down in response to my written questions or whispering back to me I resolved to tell them all, perhaps a little too forthrightly, that I had only lost my voice, not my brain. If you allow people to treat you as an invalid then as sure as eggs are eggs that is what you will be.

Thirdly, I got up and out as soon as I possibly could. In fact I was back at work within two weeks of my final operation on 29th April. Now I know that may not be possible for many and I was exceptionally young for a laryngectomee, but my point simply is try and get back to a normal routine as quickly as possible before invalidity overtakes.

I will end where I started at the beginning. What fate delivers up. I am convinced being a laryngectomy has made me better at what I do not worse. Why? Well not because of pity. I ask for none and get none. Rather, I can hold people's attention now in a way I never could before. They hang on every word because it is not that easy to understand me. The end result is people listen in a way they never would have. My career was certainly strengthened. But the strangest twist of all was 24th April. 1988 saw the birth of my first child, Esther. 1989 saw me in ICU after a disastrous second operation where it looked for a time that the game was up. 1990 saw me finish the London Marathon side by side with the nurse who had so looked after me in ICU a year earlier. From peak to trough to peak again and not once did I choose that date.

And in all honesty on balance I do not think I would change any of it had I my time over again.

## Sovereign Healthcare supports Emergency Cards

Once again it was a pleasure to be welcomed to the Mayor's Parlour on the occasion of the cheque presentation to the Trust by Mr Leslie Morgan representing Sovereign Healthcare. The generous donation of £1500 will be used to replace the stock of Emergency Cards which we provide to all Neck Breathers. Fortunately the actual card is a more manageable size when compared with the poster version held by member Doug Collins in the photo. If anyone requires a new card as their previous one is lost, stolen or strayed or even faded away then please contact the office for a replacement, free of charge.

The issue of neck breathers receiving the correct attention in an emergency has been addressed recently by the National Patient Safety Agency following concerns expressed to them by the National Association of Laryngectomee Clubs. The NPSA documents call for more training for NHS emergency staff and appropriate equipment in ambulances. For more information on this important topic contact [www.npsa.nhs.uk](http://www.npsa.nhs.uk) or phone 020 7927 9500.

### News from Nita

Nita Roberts is the Secretary of the Chatterbox Club and reports that they were proud to be invited to a meeting at the Queens Medical Centre in Nottingham entitled Masterclass by Dr Eric Blom. The meeting was attended by speech therapists, consultants and medical students from other local hospitals. Some of the information was rather technical but as patients and carers we were able to understand most of what was said and were pleased to have problems discussed in plain English.

Nita also wished to say "Thank you" to the Queens Medical Centre from Chatterbox members who think the care and after-care for laryngectomees is the best and that they are lucky to have such good treatment in the area. Thanks also to Derby Royal Infirmary for all their good work which is appreciated by the patients.



*Carole Stainton, Doug Collins and Mayor Cllr Olwyn Jennings*

### Macmillan Regional Conferences

Macmillan Cancer Relief and CancerVOICES are once again hosting a series of regional conferences for anyone affected by cancer and interested in self help and support and/or user involvement. A great opportunity to meet up and exchange news and views on current developments taking place on 4 November in Coventry, 8 November in York and 11 November in London.

For further details contact;

Heather Petty on 0207 091 2010

or [www.macmillan.org.uk/regionalconferences](http://www.macmillan.org.uk/regionalconferences)

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



**CANCER  
LARYNGECTOME  
TRUST**

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

TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS