



TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

Dear Friends

My husband and I enjoyed a relaxing month in Tunisia missing some of the bad weather but February still had more in store for us. Now it's lovely to see the garden coming to life again, in particular, we enjoy the snow-drops which we brought from our parent's garden in Halifax. The exciting news that we have been granted a Radio 4 Appeal, which we are busy working on at present, will hopefully have you all glued to your radios on 9th May. With Best Wishes from all the Trustees.

Regards

Wendy Thompson

BBC Radio 4 Appeal

We are all very excited that the Trust has been granted a BBC Radio 4 Appeal which will be broadcast at 8.55 and 21.26 on Sunday 9 May 2004 and also at 15.27 on Thursday 13 May 2004. The appeal will be recorded by a guest presenter. In addition to hopefully raising money for us it will be a very useful opportunity to raise the profile of the work we do for laryngectomees and let the general public learn more about the disability. The appeal will also be accessible from the BBC web site at www.bbc.co.uk/radio4/religion/radio4appeal.shtml We are very grateful to Victoria for all the work she has put into preparing for the broadcast.

Seminar at Rotherham Hospital

In February we were pleased to be present at a seminar entitled *A Multidisciplinary Approach to Head and Neck Cancer* at Rotherham District Hospital. We were able to talk about the trust to the delegates at the event and were also pleased to get positive feedback about our founder's book *Laryngectomy is not a Tragedy*.



Louise Bass of Weston super Mare writes:

I have been trying for several years to get Social Services to recognise loss of speech as a disability. Success at last. The recently appointed Adult Services Manager has heeded my appeals. He recently called me to a meeting with himself, the local speech therapist, an occupational therapist and a representative from the Primary Care Trust.

I was querying services for all communication impaired, which of course would mean substantial numbers involved. I know we only have about six laryngectomees in this town. Further meetings are arranged. The Manager has requested research into the number of communication impaired people and the local available support services.

The Manager, Occupational Therapist and Primary Care Trust Representative are now all having to think about impaired communication and the ensuing vulnerability.

I urge all members to bring communication problems to the attention of Social Services in their own area, doing this across the country we might achieve something.

Louise Bass

**Cancer Laryngectomee Trust
National Association of Neck Breathers**

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Speak for Th' Sen

A support group for head and neck cancer patients in the Calderdale & Huddersfield area was founded last year and decided to adopt the good Yorkshire dialect expression as its title "Speak for Th'Sen". Members of the group have enjoyed a number of social activities and in particular the photo shows the Christmas Party spirit.



Ties for Formal Occasions

In the previous issue of the newsletter Ray Mountain raised the topic of what to wear in the way of collar and tie at Black Tie events. At a group meeting the topic was discussed and some men said their solution was to buy a shirt with a larger collar size than previously worn and then a tie will fit on without causing any problems. Bill Tarrant sent in a photo to show his solution of wearing what he calls a lace or string tie. He first bought one in Spain but has seen them for sale in the UK at shops selling cowboy gear for line dancing enthusiasts. Another contribution came from Victor Smith who said that recently he wore a tie around his bare neck, it covered the stoma and filled up the vee in the shirt. It caused comment from several people so he put it down as a success and plans to repeat in the future.



Jewellery for Laryngectomees

Following the discussion about ties for men, members might be interested to hear about Marianne Hoedemaekers who makes individual pieces of jewellery specifically for laryngectomees and tracheostomies.



Each item is individually made to fit over the stoma or HME without restricting airflow. She makes items for both men and women, those on a chain can be positioned to hide the stoma or alternatively some attach directly onto the HME and can be depressed in the centre. Marianne can be contacted at jacobspt@tref.nl

Collecting Boxes -Can Anyone Help?

Just to remind you:

We have been offered some collecting boxes which will be printed with our name and logo and supplied free of charge to us. If anyone would be willing to be responsible for placing a box in a pub, club, shop, surgery, clinic or similar location and emptying the cash for us at regular intervals please contact me at the office address. Thanks to those of you who have volunteered already.



Web Site for the Trust

Work is currently in progress to create a Web Site for the trust. The plan is to have it ready for the date of the BBC Radio 4 Appeal on 9 May. The address will be www.cancerlt.org and e-mail contact can be made using info@cancerlt.org

Communication by Victor Smith

It was in May 1999, centuries ago now, that I joined with numerous Professors of Medicine and other dark arts, in the Cabinet Room of 10 Downing Street. We were there to launch the 'Challenging Cancer' seminar in advance of the white paper 'Our Healthier Nation'. It was to identify the areas which needed more energy and effort to make progress in the fight against the disease which was claiming so many lives on a regular basis and which sadly was on the increase. It had the personal backing of the Prime Minister and was led by Sir Liam Donaldson the Chief Medical Officer.

All of us were allowed roughly six minutes to address the PM and the Secretary of State for Health on our particular viewpoint. Sitting next to the CMO and directly opposite Tony Blair I was able to look him straight in the eyes as I made my presentation of a patient's point of view. In my concluding paragraph I posed the question Where do you think improvements can be made for the benefit of patients? My reply was brief:

"To paraphrase a well known politician – Communication, Communication, Communication".

That was a while ago. Has anything changed? I think not. Based on further visits to hospitals, I am firmly of the opinion that not only is there a shortage of doctors and nurses, beds and drugs, there is still an absence of communication at all levels.

It was a couple of years ago when I last had occasion to spend 12 days in Hospital. I guess I spoke about a thousand words each week, mostly to doctors and staff. The ward population changed by the hour, so by the time I'd reached a 'working relationship' with someone who could understand me, they moved on. The lady who did the dusting and polishing was the nearest person with whom I had any sort of relationship. Like me she was probably bored out of her skull but, as English was her second language, she made the effort for which I'm grateful.

Communication, in my experience as a Laryngectomee, there's not a lot of it about. I think its all about time, nobody has any to spare.

Victor Smith

Trustee Report for the Year ending January 2004



Lucy Norgate

In 2003 we suffered the sad loss of Lucy Norgate the widow of Sydney Norgate the founder of the charity. Lucy had been unwell for some time and so her death was a release for her. However, it was a very great loss to her family including her children, grand-children and great grand-children. Lucy excelled at working behind the scenes and providing limitless support to those around her. She was instrumental in the setting up of the Charity and in seeing it through those crucial early years.

Once the Charity was established she turned her attention to improving the lot of its members and took great delight in ensuring that civil servants were left in no doubt about the way in which our members could be assisted if only a little common sense could be applied. Her gentle manner concealed a fierce determination and her persistence paid off in the longer term.

In addition she understood the role of the carer which she undertook herself in relation to Sydney. As a result she could empathise

with others in the same position and more than once would talk to a partner on the telephone during the hours when the operation was taking place giving comfort and re-assurance.

Carers come in all shapes and sizes and fulfill a vital role which the trustees recognise. One of the great benefits of the lunches funded by the Charity is the opportunity for carers to meet with other carers and gain support and confidence from knowing that they are not alone.

So far as the running of the Charity this year is concerned the trustees and in particular Carole Stainton have been adopting a hands on approach after the departure of Bill Moloney. An office has been located which is convenient for Carole and should be available on a long term basis. During the year we have managed to put together some exciting plans for fundraising activities in 2004. The day to day work of the Charity has continued and we look forward in 2004 to a year of stability and consolidation.

As the Charity receives no support from Government agencies we are always very appreciative of donations, grants or legacies which enable the Charity to continue its work. Race Night is an essential part of the fund raising work and in 2003 a total of £2900 was raised. Thank you for your support.

As always the Trustees remain committed to continuing the work of the Charity and helping Larry's and their families in whatever way is most appropriate.

The Trustees would like to thank Keith Roper, Phil Briggs and the staff at HSBC, Allan Naylor, Sister Helen Chadwick, Sovereign Healthcare, Mr Malcolm Bastard & Mrs Janet Rushworth.

web site: www.cancerlt.org
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