



TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

### **Dear Friends**

Well after the storms of the early winter the weather seems to have been kinder to the UK recently. We have escaped without snow and with only about 3 frosts which made the wallflowers very sorry for themselves. They soon recovered and have been a good show. We have noticed how good the blossom on the trees has been this Spring, the downside however being that the weeds are very healthy as well.

The champagne corks have really been popping firstly for our daughters graduation ceremonies in January and then in April for our grandson's 18<sup>th</sup> birthday. We were also very pleased to welcome Carole and Michael's grand-daughter, Lucy, to the family in April. Len Hynd's poem on Mother Love, later in the newsletter, is a theme we can all relate to. The Bridlington Lunch is being held on 6<sup>th</sup> July, the weekend of the start of the Tour de France cycle race here in Yorkshire. Any member who will be in the area will be most welcome to join us at The Expanse Hotel (See full details later). Enjoy the Summer, hopefully we will have some good weather but not too extreme.

Best Wishes,

**Wendy Thompson**

### **Members Survey**

Thank you very much indeed to everyone who completed and returned the Member Survey which we sent with the recent newsletter. We have been busy with the analysis of your replies and will report in more detail in a later newsletter once the Trustees have discussed your very helpful comments. Thank you to those who offered to help in some way we will contact you soon.

It is clear that some of our long standing members were confused by the reference to a Welcome Pack as this is something which was introduced after many of you had joined. It refers to all the items which we offer to new members namely : Emergency Card, Lapel Badge, Copy of Laryngectomy is not a Tragedy, Information about Prescription Items, T-shirt or Tie, Frilly Stoma Cover (Female). If anyone would like any of these items either because they never had one or as they have become damaged or worn we will be pleased to supply them. A stamped addressed envelope would be appreciated to assist with postal costs. Please send to CLT, PO Box 618 Halifax HX3 8WX

### **Newsletters by e-mail**

Thank you to all those members who agreed to receive their newsletter by e-mail to save postage costs to the charity. This copy will be coming to you in this manner. If anyone else would like their newsletter in this way please e-mail [info@cancerlt.org](mailto:info@cancerlt.org) to request this method of delivery.

## Time to get your running shoes on!

Each year the Charity has places for runners in the London 10K Charity race and this year is no exception. Do you know anyone who would be interested in running 10K for the Charity? Since 2009 we have had support from many runners including friends and family of larrys, doctors, nurses, speech therapists and work colleagues. The race is in July so the weather has varied from sunny to warm and wet. However, the enthusiasm does not reduce no matter what the weather conditions are. This year the race is on Sunday the 13th July starting at 9.35 am. Runners must be at least 15 and capable of completing the 10K in less than two hours (so that counts me out!). Each runner will have chip timing and will receive a medal and certificate. They will also be able to download an official race photo. The event is in the centre of London and the streets are closed to traffic making it a wonderful experience for all the spectators. The route takes in Trafalgar Square, the Embankment and the Houses of Parliament. Many different charities are represented both large and small and there are many different costumes to look at.

So, if you know anyone who might be interested please encourage them to contact us. We would be delighted to hear from them at CLT PO Box618, Halifax HX3 8WX or e-mail [info@cancerit.org](mailto:info@cancerit.org)



## **Margaret's Story**

In July last year we were pleased to receive a letter from Margaret Joy after we had sent her a Welcome Pack when she became a member. With Margaret's permission we would like to share some of her letter as we feel it might be of interest to other laryngectomees.



*My operation was in February 2011, and because it was the last line of treatment, after chemo and radiotherapy had failed to remove the tumour, the decision to do a laryngectomy was taken fairly quickly, and so I was ill-prepared. I was given a pack of leaflets, including your father's booklet (Laryngectomy is not a tragedy). He was obviously a remarkable man, and a wonderful inspiration. As I read his book, several times, I really did feel: If he can become so proficient and self confident with pharyngeal speech, then perhaps I can too. I was determined to work at it.*

*Unlike some surgeons, mine did not automatically insert a speaking valve as part of the operation, and I agreed with that:*

- a) not wanting to go through the difficulties I had been told about the cleaning, re-fitting, possible infections, etc, connected with these, and*
- b) feeling that with the aid of speech therapy – and inspired by your father's experiences – I would be able to learn pharyngeal speech.*

*During my working life I had taught languages, told stories to classes of children, used my voice in drama and speech for many years. I liked to get to know people by encouraging them to talk; I was a good communicator. My voice was ME.*

*However. However – In spite of a year with an excellent speech therapist, I found pharyngeal speech very difficult in practice. It is very slow, it tends to make me cough and become breathless. I also do think that women produce less timbre anyway, so I was unable to produce much volume or project the sound. Nor had I your father's ability 'to burp at will from an early age'!*

*Over the months I became what my speech therapist called a 'total communicator'. I would use what sound I was able to produce, I would articulate clearly, and gesture if necessary (what your father calls 'consonant speech and mime'). I soon came to realise that most people understood me fairly easily on a one-to one basis (if there was no competing background noise) and in a good light so that lip/face reading is easier. I also came to realise that many people my age (in my 70's) are hard of hearing and were not able to hear what sound I was able to produce. I also realised that many people are not able psychologically to watch my face while I speak. Perhaps they are not used to so much eye-contact. Perhaps I am too slow. Perhaps they are embarrassed for me, or for themselves. Perhaps they want the conversation to centre round them and can't wait for me to reply OR they make sure they hog the conversation as a way of avoiding my stumbling efforts. (I've learnt such a lot about the psychology of communication since my operation!)*

*All of this preamble is trying to explain why eventually, and somewhat reluctantly. I accepted an electronic voice, a Servox, from my speech therapist. It's useful because I can speak more quickly and understandably. But as you know, it has the disadvantage of sounding monotonous and 'Dalek-like'. So in a way I feel I have failed your father. I do wish I had had the advantage of having him come to play dominoes with me and encourage me in pharyngeal speech!*

**With very best wishes, Margaret Joy**

Thank you Margaret for agreeing to share your experiences. I am quite sure that Sydney would not have allowed you to call yourself a failure – you are communicating.

## A MOTHERS LOVE

By Len A.Hynds

This beautiful poem is dedicated to baby Lucy who was named after her great-grandmother Lucy Norgate who dedicated so much of her time to helping laryngectomees in the early days of the charity.

Love usually has conditions,  
in one way or another,  
but no conditions do exist,  
between a child and its mother.

From long before the day of birth,  
they form such natural bonds.  
That love a mother always gives,  
and the way the babe responds.

Just see them when they are together,  
and imagine them apart.  
No other love's quite like it,  
it can melt the hardest heart.

The love between a mother and child,  
is impossible to explain.  
It's just a simple fact of life,  
and will always be the same.



## Summer Lunches

Lunches will be held this year in Blackpool at the Savoy Hotel on Sunday 15<sup>th</sup> June. Anyone wishing to attend please contact Mrs Sandra Waddington, 76 Rutland Avenue, Poulton-le Fylde, FY6 7SA Tel 01253 899531

The lunch in Bridlington will be held on Sunday 6<sup>th</sup> of July at the Expanse Hotel. Please contact Wendy Thompson, 10 Meadow Drive, Market Weighton, York, YO43 3QG Tel 01430 871561

If any clubs would like to request financial support for a lunch event or outing we would be pleased to consider your request. Please contact us to ask for a Grant Request form to complete at CLT PO Box618, Halifax HX3 8WX or e-mail [info@cancerlt.org](mailto:info@cancerlt.org)

web site: [www.cancerlt.org](http://www.cancerlt.org)

email: [info@cancerlt.org](mailto:info@cancerlt.org)



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