



TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

Dear Friends

Wendy Thompson is very busy at present with family caring responsibilities. She has asked me to send her best wishes to everyone and says she is looking forward to seeing everyone at the Bridlington Lunch in July.

Best Wishes

Carole Stainton

Trustee

Members Survey Results

In 2014 we carried out a survey of members. The purposes were to find out what our members and relevant health professionals thought of our services and to find out if any members would be interested in volunteering to help with any aspects of running the charity. We were very pleased that we received 82 responses and we were particularly encouraged by some of the very positive comments we received. Some of the responses came from people who had been members for over 16 years whilst others had been members for less than a year so we were pleased that such a wide range of experience was included. It was also helpful to us to hear about those aspects of the Charity where you felt there was room for improvement. We are working on those areas now.

So far as the results are concerned, it was clear that the Welcome Pack, the Travel Guide, the Newsletter and Race Night were important to many of those who responded. The fact that we are able to make small grants to individuals was recognised as important, particularly by health care professionals.

We are aware that the Welcome Pack has changed over the years and we do have a new edition of the book Laryngectomy is not a Tragedy. Here is a list of the items in the welcome Pack. If you did not receive any of these and would like them please let us know.

Book – Emergency Card – Lapel badge – Prescription List – T shirt – Tie/Frilly

So far as the Travel Guide is concerned, you may be aware that Paul Cantlie who prepared the Guide sadly died in 2014. It is our intention to continue to produce the guide. We are aware that the guide must be reviewed on a regular basis as the information in it will change. It cannot be foolproof but it is a valuable tool.

The Newsletter is a significant part of our service and as a result of the feedback received we are hoping to include in it more information that is of value to members.

The majority of those who responded were happy to receive the Newsletter by email. This is very helpful to us as it helps to keep our costs down. Therefore, if any other members are happy to receive Newsletters by email please let us know by emailing us at info@clt.org. However, we are committed to the use of paper and will only use email if that is your preferred method. As the trustees have an average age of over 68, we do remember when paper was the only option!

We received a positive response from 15 people to the idea of helping the charity on a voluntary basis and we are in touch with those who responded. One area for improvement was the suggestion that the profile of the Charity be raised in hospitals. This is an area where our individual members are so important. If you would be able to pass on information about the Charity to your local hospital please let us know so that we can give you the relevant information.

As we expected, the survey results have given us plenty to think about and work on but, more unexpectedly, we also received many words of encouragement.

Thank you to all who responded. As was suggested by one of the responses, we intend to "Keep up the good work"!



Helping Our Family and Friends

We are putting together a leaflet for younger friends and relatives to help them to understand what a laryngectomy is and how to help. We all have memories of our father Sydney and remember the questions that we wanted to have answered. However, we are sure that you will also have experiences of questions that you have been asked and comments made. Some of them may be humorous and some may be more difficult. It would be very helpful if you could tell us about any experiences you have had that we could address in the leaflet. Here are some suggestions we have thought of so far.

- Why is there a hole in your throat
- Will it heal up
- Why does your voice sound different
- Is it hard to swallow food
- Do you eat through your neck
- Do things smell different
- Can you whistle
- Does your neck get cold

Please send any comments or suggestions you have to info@cancerlt.org or by post to: CLT, PO Box 618, Halifax HX3 8WX.



Summer Lunches

Once again we are arranging two Summer Lunches this year.

The lunch in Bridlington will be held on Sunday 5th of July at the Expanse Hotel. If you would like to attend please contact Wendy Thompson, 10 Meadow Drive, Market Weighton, York, YO43 3QG Tel 01430 871561

The Blackpool lunch at the Imperial Hotel on Sunday 14th June is being arranged by Mrs Sandra Waddington, 76 Rutland Avenue, Poulton-le Fylde, FY6 7SA Tel 01253 899531

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

Champion Fundraiser Linda

Member Linda Bailey and her family have organised a number of Charity Balls for ENT at Lincoln Hospital, the Royal Marsden Hospital, Lincolnshire Air Ambulance, Macmillan Nurses and the Special Care Baby Unit.

Well Done to you all and thank you for the photo showing you in your finery ready for a ball, Linda and her husband are on the left.



Qualified

In May 2013 we included an item in the newsletter about member Trisha Morrison who was studying to become a counsellor. We are pleased to provide the latest news from her:

I am so pleased to be writing this to inform you all that on 17th November 2014 I qualified as a Counselling Practitioner. Four years of hard work had finally paid off and here I am at the age of forty one pursuing a new career with a feeling of excitement for what my future career may bring. Not only did I receive my qualification in November 2014 but I was also offered my first contract as a paid Counsellor two weeks after gaining my qualification. I am now counselling survivors of sexual abuse/violence which I absolutely love. One of the biggest things I have taken from all of my client work and training so far, is just complete amazement of how resilient people can be in the face of adversity. Doing the work that I do just fills me full of appreciation and I feel humbled and privileged to help and

support people on their journey of recovery.

To quote the late Sydney Norgate, "LARYNGECTOMY IS NOT A TRAGEDY." I am living proof, as are many others, that there certainly is life after a Laryngectomy. I would like to take this opportunity to thank Carole Stainton and all at the trust for their support. It has been very much appreciated. THANK YOU!! Future plans for me include counselling patients and families of Laryngeal cancer. This will happen I am sure. Thank you all for taking the time to read my journey so far.



The Lary choir



An interesting article has been submitted by member Sara Brading:

Always being one to mimic people and doing different accents for a laugh as sort of a party piece with family, the idea of having my vocal chords removed was horrifying. "You can't do that" I said, "I won't be able to talk. I have a young daughter with additional needs, I need to be able to talk to her".

Thanks to an incredible team of people, surgeon, Speech & Language Therapists, & Macmillan Nurses, I can still talk.

My operation was February 2012. Chemo and radiotherapy was tough, but when I got my speech valve, things started to look better. However I was very conscious about the way I sounded.

I avoided using the phone, as most people assumed I was a man, or they couldn't understand me at all. In the end I pretty much stopped using it. In fact, I avoided speaking to anyone even face to face, because I got fed up of repeating myself. So, even though I'd got a voice back, I wasn't confident using it, & it was hard work

Then, along comes a rathy cheeky chappy by the name of Thomas Moors, who, with the help of a Speech & Language Therapist (Lizz Summers), & two Opera singers (Laverne Williams and Lucie Davienne), starts voice rehabilitation sessions, with a mad idea of starting a Choir.

Hmmm I thought. A Choir, with people with no vocal

chords. Really?

Well up for a challenge I decided to go along and see. Apart from meeting some amazing people, I have learnt so much about the voice.

As Laryngectomees (and I hate that word), I think its incredible that we can talk at all. But, it can be improved on.

The voice rehabilitation sessions have taught me how to breathe differently, in the way that a singer would, to get much more control. We use different techniques with the vowels and consonants to get more intonation in the voice. I have to tell you, I have been asked to Moo, Meeow, and ee-aw in the sessions (very funny), but it works.

I used to love to sing, and I never thought it would be possible, but I did sing We Are The Champions by Queen in front of them all. Not sure it was great pitch wise, but I did it.

By breathing differently, being aware of my diaphragm, I have so much more control over my voice. I can shout, I feel more confident on the phone. I can read a poem with the right intonation. I can talk to my daughter properly and read her a book, and everyone I know has commented on how much clearer my voice is.

Find this man, this Thomas Moors, and get on board. You've nothing to lose. Who knows we could be the first Alaryngeal choir on Britains Got Talent, Ha Ha. But, if not, you might just improve your voice.



Voice rehabilitation group sessions are currently taking place in Cambridge, and groups are due to start soon in Luton and London. If you would like to take part, or register interest in establishing a group in your area, please contact Dr Thomas Moors on thomas.moors@gmail.com or Ms Lizz Summers on elizabeth.summers@city.ac.uk

Presentation to Mr Pracy



On the 22nd January 2015 a presentation took place at Queen Elizabeth Hospital to Mr Paul Pracy Consultant ENT surgeon. This was for his work in editing the new material in the second edition of the book Laryngectomy is Not a Tragedy which is published by the charity. The new chapter was written by a Birmingham graduate Dr Nicola Oswald who is also the granddaughter of the founder Sydney Norgate.

The book was written by Sydney Norgate, the founder of the Charity and himself a laryngectomee in order to help other laryngectomees to learn to talk again. It is full of practical advice and information as well as reassurance. The style is straightforward and humorous and includes cartoon illustrations to help the patient on the road to recovery. The book was written over

25 years ago and a new edition was brought out in 2013 to provide the latest information on new speech methods, lifestyle information and future developments.

The presentation was made by Trustees Rosalind Oswald and Wendy Thompson in appreciation of Mr Pracy's help and support. The book is available from the charity and is supplied free of charge to all laryngectomees and health professionals who work with laryngectomees. The website for the charity can be found at cancerlt.org and the book can be downloaded from the website.



Ray Coates Song for 20-20 Voice Charity

Member Lynne Britzman has sent some interesting information:

I am a lary and have been for over 5 years. I was recently put in touch with a local man who actually had tonsil cancer, but is raising money and awareness for all head/neck cancers by working with a charity called 20-20 voice (based in Leicester).

The gentleman in question... Ray Coates, has produced a song and accompanying video, with which he wants to raise funds... ideally in order to produce an album, which is then a sustainable income for the charity 20-20 Voice.

His story is told on the youtube video accompanying his song. I am wondering if his story is something your newsletter would be interested in featuring.

Lynne Britzman

I contacted Phil Johnson of 20-20 Voice who replied as follows:

Ray Coates is one of our dedicated area representatives who fully supports our "Awareness Campaign" as it was the early diagnosis that saved him from the full surgical horrors that many of us suffer. His beautiful song is now on our website here (<http://www.2020cancerappeal.org/your-page/say-hi-to-mr-ray-coates/>) and really does deserve some serious airtime!

Ray has already had this song included in a school production to raise funds for this charity and the song is also featuring at the Aylesbury Theatre (sometime in April)

Phil Johnson

web site: www.cancerlt.org
email: info@cancerlt.org



CANCER
LARYNGECTOME
TRUST

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