



TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

Dear Friends

This newsletter is coming from Carole as Wendy and her husband are enjoying an extended break on the Algarve.

First of all a very big Thank You to everyone who participated in Race Night 2004 on which we were delighted to make a profit of £3300. The full results appear later in the newsletter and all prizes were despatched before Christmas but if anyone has a winning ticket and has not received their prize do please get in touch.

We had a rather worrying time back in October when our eleven year old Labrador dog Lucy had to have surgery on her larynx as she was having difficulty with her breathing. It was the second time she had to have the operation to tie-back her larynx and at one stage the vet thought he might have to carry out a tracheostomy. If that had occurred then she really would have become the first canine members of NANB! I am sure you will all sympathise with her waking from surgery and not being able to bark. She has made excellent progress over the past three months and even a bark, albeit rather strange, has returned so she plays noisily with Anna our younger Labrador.

Many thanks for your Christmas Greetings to us and all the very best for 2005 to you from all the Trustees.

Regards Carole Stainton.



Neckwear for Laryngectomees

For several years we have offered lacy stoma covers for female laryngectomees and we were very interested to hear from Audrey Lamb about the beaded necklaces which she makes.



She enjoys making them so much that she is willing to make them to order in whatever colours are required and to the appropriate neck measurement. They cost £7.50 inc post & packing and Audrey can be contacted at Laburnum Cottage, Gate Helmsley, York YO41 1NB.

**Cancer Laryngectomy Trust
National Association of Neck Breathers
PO Box 618
HALIFAX HX3 8WX**

**Telephone/Fax 01422 205522
web site: www.cancerlt.org
email: info@cancerlt.org**

Charity Registration Number: 326653

A Poem to Sarah Button

Many new members have delightful stories to tell us of the care they have received during their cancer treatment. One such person is Len Hynds who has submitted this poem he wrote to Sarah Button "A shining example to all those wonderful ladies who are so skilful in dealing with the Laryngectomees problems".



Len Hynds

My Nurse (A Truly Remarkable Young Lady)

I thought the cancer would kill me,
the doctor would try his best,
but who gave me the courage, to calmly,
face the knife, with my mind so at rest.

T'was Sarah my nurse, on that fearful night,
who knew my every thought.
Her soft-spoken words, to stop my fright,
the soft hand, as fear I fought.

Who gave me the will to laugh at pain,
that nurse with the angel face.
Who gave me the will to live again,
that nurse with the boundless grace.

Doctors may carve, cut, and sew you,
but the soul they can never reach.
It takes the heart, of a woman true,
as love they give to each.

Quit Smoking Campaign

In the last newsletter we invited members to give their comments on the TV laryngectomee ad being used as part of the Quit Smoking campaign. We received a number of letters and e-mails and thank you all for the comments. As might be expected there were a number of different views expressed, some people did find the ad distressing, bringing back memories of a very difficult period in their life, while others felt that 'shock tactics' are required and that laryngectomees should not be shielded from use in this way.

Clay Cross Rotary Club

Laryngectomee Ray Mountain accepted a cheque for £250 from the Rotary Club of Clay Cross at a presentation evening at which a number of charities received cheques to support their work. The photograph shows John Hodgson, Club President, making the presentation for Cancer Laryngectomee Trust to Ray.



Ray Mountain and John Hodgson

Bratton Silver Band Concert

We are very honoured that the Bratton Silver Band — one of whose players, Les Wood, is a laryngectomee — are to hold a concert on our behalf on Saturday 16 April 2005 at 7.30pm at Devizes Corn Exchange.

Tickets cost £8.00 and can be obtained from Mrs Lisa Hill, 49 Wiltshire Way, Westbury, Wiltshire, BA13 3XD, Tel 07981 533003 or secretary@brattonsilverband.co.uk



Bratton Silver Band in action

News from Louise Bass

I recently accepted an invitation to join the regional advisory group of the Disability Living Centres Council. I was asked to give a talk at the Council's Annual Conference in Manchester at the end of November 2004. It was my first public 'speech' and scary. I just managed to get through. I had printed a duplicate copy and had one of the organisers sitting by in case I could not manage. I just felt it was too good an opportunity to publicise the lack of speech.



Louise & Julia Holley at Volunteer's Fair

"I am a laryngectomee which means I have no vocal chords and, breathe only through a small hole in my neck. The vocal chords were surgically removed due to cancer early in 1994. There are about 2000 laryngectomees in the UK, a forgotten minority.

The long term survival rates post surgery are very good, there are laryngectomees surviving 30+ years after the operation. Improving the quality of daily life is therefore important. The main needs for any person with severe communication impairment are understanding and publicity to extend this understanding, as well as relevant legislation to protect us in our vulnerability.

Apart from losing our voices we are extremely vulnerable to abuse. It is very easy to abuse a person who cannot shout back. There is very little understanding of severe communication impairment. It is an isolating impairment. The use of hearing, physical and vision aids has become acceptable but not communication aids, which tend to be treated as an embarrassment.

Research undertaken over a 1000 different households in the North East has shown that people with severe communication impairment tend to stay within their own small circle of family and friends. Some were found to be in denial despite obvious difficulties.

Earlier this year I attended a local disability conference. 120 persons were present. The physically impaired gathered together to talk, the vision impaired were in a group from their strong local association, the hearing impaired were in two groups together with their interpreters, then there was me. As usual the only person without communication.

We are treated with the utmost suspicion on the telephone, and sometimes ridiculed.

I personally have been subject to verbal abuse whilst shopping, because another potential customer has not understood, or heard, my attempt to say 'excuse me' as I attempted to reach an item.

I have lost my sense of smell so food burns unknown to myself.

I cannot draw food into my mouth which often means I spill it and stain clothes.

I have physical limitations due to breathing difficulties.

I have swallowing difficulties so can rarely eat out, as a result most of our holidays are self catering.

I am vulnerable, I cannot call for help, under stress I have no communication.

I cannot laugh or cry, there is no provision for assistance for emotions which are blocked in. All communication is stopped by background noise.

We seem to fall into a vacuum between the support and provision for mental and physical impairments.

Meetings in general do not provide for the input of a person with severe communication impairment. We lack representation on decision making bodies.

This is a very real sensory impairment and needs to be given equal rights as are accorded to all other impairments and minority groups. There is a very definite need for increased understanding and support of our needs in the NHS, Social Services and all disability organisations."

Servox Presentation

Following the very successful BBC R4 Appeal the trustees decided to present two Servox machines to the Calderdale Royal Hospital for use by patients immediately after surgery. Speech Therapist, Mandeep Syan, said "The equipment is essential to patients quality of life".



CLT's Carole Stainton presenting two Servox machines

Race Night 2004

Winners of the Absent Owners Races

Race 1	Herbert J B	Mollie Jayne	Race 20	Jackson Keith	Chernside
Race 2	Tarrant W J	Wind Swepted	Race 21	Ball Peter	Finn
Race 3	Hibbert Jean	Baby Cain	Race 22	Ronald R	Nicola Jane
Race 4	Rothwell Malcolm	Little Cal	Race 23	Holme Alan M	Finmental
Race 5	Keefe Ann	Lindens Lad	Race 24	Newberry G	Belinda
Race 6	Fairclough Clifford	Nellies Nag	Race 25	Thorogood Geoffrey	Jackie's Delight
Race 7	Bird M	Birdie	Race 26	Sankey Paul M	Silver River
Race 8	Neale J	Georgie Boy	Race 27	Miller M	Great Aunty Mau
Race 9	Helps Kenneth	Werburghs Way	Race 28	Thompson Liz	Sunny Smile
Race 10	Roper Keith	Ever Hopeful	Race 29	Vaughan D	Lancashire Hot Pot
Race 11	Crossen G R	Our Emma	Race 30	Cotter V	Liberty Lara
Race 12	Cross Richard	Binary Code	Race 31	Davies J B	Frimley Park F O T
Race 13	Cook Veronica M	Speedwell	Race 32	Mountain Ray	Sugar Loaf
Race 14	Lawson D	Muchty Maiden	Race 33	Tomlinson B A	Ralph
Race 15	Dow Alex	Glasgow Gal	Race 34	Johnson Peter	Thunder
Race 16	Collins Chris	Dobbin	Race 35	Starey Peter	Apple Pie
Race 17	Beadnell Kenneth	Kalumity	Race 36	Tucker Mr & Mrs	Black Jack
Race 18	WAF Lois Smith	Jack of all Trades	Race 37	Pignatelli Colin	Juliet
Race 19	Irwin David S	Babe Ruth			



Carole Sainton presenting the Race Night Trophy to Malcolm Rothwell

Winners of Raffle Prizes

First Prize Mini Break at the Sawrey Hotel 020603

000229 003792 004417 004677 004921 005154
 005389 005830 005872 006044 006175 006411
 007937 007953 008267 008397 009047 009140
 009544 010368 010413 010908 011100 011398
 012323 012730 012942 013010 013989 014053
 014243 014977 014617 015447 015748 015930
 015991 016238 016332 016833 017067 017201
 017669 018179 018473 018543 018797 018961
 019131 019329 019557 019619 019792 020652
 020723 020903 021600 021603 022508 022584

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