

TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

Dear Friends

As I sit writing to you, looking out into the garden I can see the snowdrops starting to appear. A sure sign that Spring is on its way, lets hope its not too long in coming! I think we have all had enough snow and ice and I do hope you have managed to keep warm.

Race Night once again was very successful thanks to your support. The application forms came rolling in and we really enjoyed reading your very inventive horse names. There was even a very light hearted attempt at bribing the Course Steward to favour a member's horse. I chuckled as I thought of how our founder Sydney Norgate would have enjoyed reading that letter. The income of just over £4000 lead to a profit of £2500 for the charity which just shows how much support we receive from you all. The results and prizes were all sent out before Christmas.



Last time I said I would tell you about our holiday to Turkey but unfortunately it did not take place so instead we enjoyed a coach trip around the Bath and Oxford area. We were pleased to be able to meet up with our sister Ros and family. This year we are making up for last years disappointment and have so far booked a 6 day cruise of the Norwegian Fjords and a trip to Scotland. We are also planning a very emotional journey to Greece to visit the grave of our sister Janet who sadly died in November. On a lighter note there is the Royal Wedding to look forward to incidentally it's the day we set off on our cruise how inconsiderate of them!

Best Wishes, Wendy Thompson, Trustee

From Land's End to John O'Groats

Member Kim Winterton is very proud of her husband David who arranged a fund-raising adventure with his friends Dave Hatton and Ken Grice. The two Davids cycled from Land's End to John O'Groats with Ken providing the support party in a campervan. Each day went exactly to plan and the trio raised over £3000 which was shared between Macmillan Cancer Support and the Cancer Laryngectomy Trust.

Well Done and many thanks to you all



London 10K Race - Volunteers sought for 2011

The London 10k Race is held in July each year and enables runners to enjoy running through some of the most famous parts of London (including the Embankment, Trafalgar Square and past the Houses of Parliament) on roads closed to traffic in order to raise funds for their favourite Charity.

When my husband, daughter and I attended the London 10K in 2009 to support the CLT runners the event was truly inspiring. My daughter and husband both said they might like to consider running in 2010. So what actually happened?????????

After a certain amount of “Should I – Shouldn’t I” we were able to have a team of 10 runners at the 2010 event including both our daughters (Elly and Nikki) plus respective boyfriends (Graeme and Kev) and other friends (Lizzie, Rachel, and Lilian) two speech therapists from Derbyshire (Sarah and Kate) and Len Hynds grand daughter (Louise) who is a serious runner and had competed the year before.

We had learnt from the previous year how to organise ourselves and stayed near to Trafalgar Square so that our hotel was available for showers after the race (I just hope the hotel wasn’t metering the water!). We gathered in Trafalgar Square at 8.00 am and hoped the temperature would not climb too high. As one would expect there were the usual questions about how they could possibly have agreed to run 10K but we were there to support and encourage. As last year the atmosphere was so friendly and the weather was very kind.

We had improved the T shirts by putting a logo on the back as well which was a great help with recognition and profile raising for the Charity. We had also joined Just Giving so that donors could support the runners via the Internet. This was very successful and resulted in funds coming in from as far away as Athens!

There were 25,000 runners supporting Charities large and small. The first runner to go through Trafalgar Square was an expert who had been invited to set off the race. He sprinted past us at an incredible speed and, if anything, the motorcycle escort seemed to be getting in his way! There were runners dressed as zebras, chickens, deep sea divers and very overweight male ballet dancers complete with pink tutus! Our runners looked very smart and were all determined to achieve a good time as well as raising funds.

We moved down to the Embankment to see them run under one of the bridges and I was able to talk about the Charity again on one of the mobile microphones. From there it was back to Trafalgar Square to meet the runners again. They were tired but clearly exhilarated by what they had achieved. The Speech Therapists were quick to point out that there are a lot more hills in Derbyshire where they had been training! We were able to take lots of photos including the medals that had been handed out and we all enjoyed a refreshing drink to celebrate. So do you know anyone who would enjoy taking part? It is an unforgettable experience and we are looking for 2011 runners already.



Leeds Run for All

Claire Mercer and Kate Waterhouse, who are both nurses on the ENT ward at Calderdale Royal Hospital, took part in the Jane Tomlinson Leeds Run for All on behalf of the charity.

They raised the splendid sum of £287 and joined members from West Yorkshire at the Christmas Lunch to present their cheque to the Deputy Mayor of Calderdale.



Hospital Heroes

Southampton University Hospitals recently introduced a monthly award for departments competing for recognition of exceptional service. One of the very first has been awarded to the Laryngectomy Drop-in Clinic.

The University Hospitals Trust run two hospitals in the city; the Southampton General, a centre of excellence where laryngectomies are performed, and the Royal South Hants where post-operative care is provided for these patients and their carers every Tuesday morning at a drop-in clinic. This has been running in its present form since 1999 with the same Macmillan Clinical Nurse Specialist (CNS), Caroline Hampton, who established it.

The essence of the clinic is informality and companionship. Because patients can rely on the clinic being open, appointments are unnecessary, saving the hospital administrators the cost of running scheduled appointments requiring secretarial time and postage. One treatment room is set aside for changing valves and other minor procedures and a small waiting room is made available as a dedicated annexe to the main ENT Outpatient waiting area.

A common affliction is a powerful bond so a group of laryngectomees will be quite garrulous given half a chance, and an electric kettle, tea, coffee and milk are provided by Friends of RSH to aid the relaxed atmosphere in which these clinics are held. Very seldom are there fewer than two patients who need new valves and occasionally there are as many as six or more, particularly before bank holidays. As often as not three or four patients drop by just for the chat and social contact and require no medical attention.

Clinical staff is drawn from an expert pool consisting of the CNS, two Specialist Speech & Language Therapists (SLTs), and two Head & Neck (H&N) specialist nurses. A normal clinic will be handled by two of them, one from each discipline; in the case of a complex condition a patient may be transferred to the main H&N clinic which takes place the same afternoon. A steady stream of nurses, trainees and others wishing to extend their experience is encouraged to attend the clinic with the result that any patient finding they need urgent and immediate attention can go to the H&N surgical ward at Southampton General and get specialist treatment without going through possible delays in A&E.

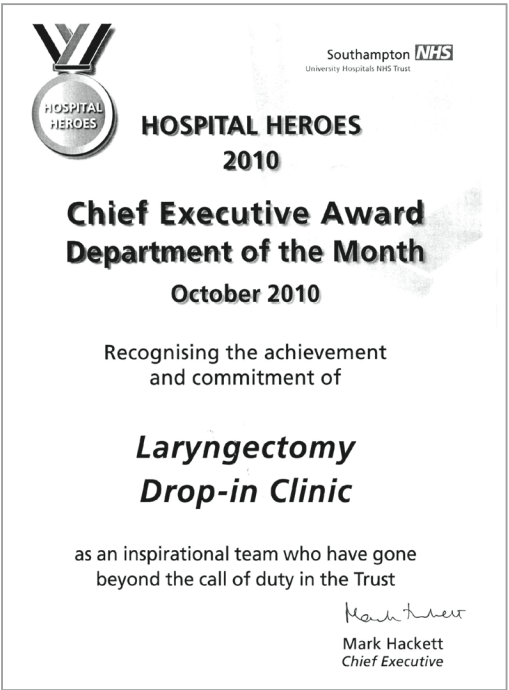
The social aspect of the clinic is one of its major features and allows new laryngectomees and their carers the chance to develop their rehabilitation with medical and peer help and see there is plenty of life after this major piece of surgery which can have such devastating effects. Discussion of aspects of life after laryngectomy is based squarely on experience in all forms and combinations, whether medical, practical or even the financial aid that can be claimed. Open discussion of this sort also helps the clinicians broaden their own experience and understanding of the life of a laryngectomee. Any hospital questioning the number of staff required to offer these services should consider how seldom these patients have to be seen by consultants, registrars or other members of hard-pressed oncology teams as a result of the Tuesday clinics. It is the combination of the medical and social aspects that makes these clinics so exceptional. There is none of the nervous silence that is usual in a hospital waiting area and the clinic constitutes its own highly effective patient support group.

Paul Cantlie

Fund Raising by Rosa

Members might recall that Rosa Taylor, daughter of laryngectomee, Peter, carried out a parachute jump as a fund-raising activity a few years ago. Since then she has been a regular supporter and recently arranged a Christmas raffle at Blue Apple Catering where she works.

Many thanks Rosa



David's Story Part 1

A recent new member David has offered to write about his experiences of becoming a laryngectomee:

NOBODY SAID IT WOULD BE EASY

There was a nurse beside me I can't remember the colour of her robes, a couple of doctors, or may be surgeons hanging around, and one of those lazy-mans injections thingies in my arm. You must know what I mean. They stick in early in the day, and just have to screw the hypodermic into it. I worked out then and there that it was for nurses who were squeamish about needles.

Then as the sleepy stuff was being pumped into my arm, without a by your leave, someone tried to poke one of those lookie in your throat, by poking it up your nose things. Somehow, managing to indicate that they had the wrong nose hole, they swapped nostrils and up it slid, a monitor was swung into view, and I watched in a dozy way as it wound its way down my nose into my throat, I saw two apertures which I assumed were the way into my lungs, and that was it. Out like a light, I seem to remember one of the surgeons saying, he will be away with the fairies when the two holes become one, but whether thats what happened I have no idea.

It's wake up time, I know that because someone has been nonstop saying, come on David wake up, time to wake up, this went on and on, untill it struck me "it's me they're talking to," that made no difference, my eyes stayed shut, I was pain free for the first time for months, and to say I was dozy would be an under statement. "Would you kindly bugger off and leave me in peace" was the thought in my head, but the wake up call continued.

"Maybe, I thought, if I open my eyes, the voice will stop, go away and leave me in peace." No such luck, and I slowly surfaced, I had no chance to nod off again, I went to say something, nothing worked!

The nurse handed me a pad and pencil. Have you ever tried to write when you are stoned out of your head on goodness knows what prescription drugs. Now, talking needs no coordination, writing does. So, I wrote totally illegible words which meant absolutely nothing to the nice nurse. "Let's leave the writing bit for the moment," he seemed to say, I nodded, which pulled the tube which went into a hole in my throat, the pull was actually on the stitches which held it in place. I couldn't believe it, the pain was more than the sum of the stuff that had been done to my neck. Wierd! "Sod this" I thought, back to sleep was the best thing to do, there was no attempt to stop me, I guess I had proved I was alive and sort of compos-mentis. WRONG, Nurse man came back and we went through the wake up procedure again. Thus it went on, trying to communicate via the pencil and pad. Well the staff had no problem, all they had to do was talk to or at me. Me, I tried to talk for the first time, now I knew that my voice box and most probably other bits and bobs had been removed and added to the Brighton area land fill site, but I had no idea this meant that whispering was impossible as well as speech. I believe I sort of flapped around opening and closing my mouth like a demented goldfish, and making bubbling sounds from my new blow hole. This was total rubbish!

Best regards ,

David

Brenda's Easy-to-Swallow Cookbook

Produced by Brenda Brady, in association with the Mouth Cancer Foundation, Brenda's Easy-to-Swallow Cookbook is for mouth cancer sufferers, and anyone who has difficulty chewing and swallowing food. The softback book contains 40 pages of recipes and tips, from various people, including fellow sufferers and celebrity chefs Nigella Lawson, Rick Stein, Antony Worrall Thompson and Phil Vickery, who all kindly gave recipes for free. Following Brenda's death in 2008, her husband John finished the book, and the first edition is now available to buy for £10 (+ £1.50 pp) from Mouth Cancer Foundation, PO Box 498, Wakefield, WF1 9AW Tel 01924 950950 www.mouthcancerfoundation.org

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