# CANCER LARYNGECTOMEE TRUST

Charity Registration Number: 326653

# TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

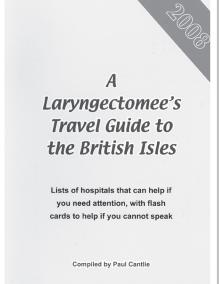
## Dear Friends

This year Bill and I spent our winter holiday in Cyprus, enjoying it very much especially as it has a Greek influence which we love as did our Mother, Lucy. We did have snow one weekend which postponed our trip into the mountains for a week.

Recently we made a trip to Derbyshire and took the opportunity to see Carole's grandson, Marcus again. He is quite a chatterbox now once over his shyness which didn't take long.

Bill is busy getting his vegetable and flower seeds planted before we make a short trip to Holland to see the tulips. Hopefully for everyone the summer will be long and sunny and we will be able to get out and about making use of our new National bus passes. It's coming round to the Summer Lunches once more and Bill and I will be present at Bridlington meeting up with some of our members and partners.

### **Best Wishes Wendy Thompson**



# New Edition A Laryngectomee's Travel Guide to the British Isles 2008

We have recently published a new edition of the Travel Guide prepared and updated by Paul Cantlie who lives in Hampshire and had a laryngectomy in 2001.

The booklet provides locations and lists of all hospitals believed to handle emergencies of the type that laryngectomees may suffer. Small maps show the spread of towns with suitable hospitals. There is an Emergency notice for the reception staff or A&E and the next page gives a list of the usual conditions to help a voiceless laryngectomee indicate what the problem is. The rest of the section lists the different hospitals, their addresses and main details.

The on-line version of the guide has a more convenient format for printing than previously and can be down-loaded from our Web Site www.cancerlt.org. If you would like a printed copy please send a stamped self addressed envelope at least 7.5" by 5.5" (18.5cm X 13cm) bearing a 1st or 2nd class stamp to CLT, PO Box 618, Halifax HX3 8WX marking your outer envelope Travel Guide.

# Winners of 1st Prize in Race Night Raffle

Member Les Bower writes:

Sincere thanks for the weekend at the Expanse Hotel in Bridlington, the hotel, staff and food were exemplary. Thank you to the trustees for choosing such a nice place for the winning raffle ticket.



Les and his wife with waitress Gemma

#### **Trustees Report for Year ending Jan 2008**

Another year has flown by and it is time to reflect on the work of the Charity over the past twelve months. Carole Stainton in her dual roles as trustee and manager and assisted by trustee Wendy Thompson has continued to extend and strengthen the Charity. This is clearly reflected in the number of new members joining this year.

As a trustee, I am kept fully informed of the activities involving the Charity. Rarely a week goes by without an e-mail from my sister Carole asking for approval for a grant or informing me of some other event or fund raising activity. Recently I had occasion to read again the book "Laryngectomy is not a Tragedy" written by Sydney Norgate, and think about all the events that have happened since I sat in the kitchen in Halifax and he told me that, at the age of 67, he had been to see the GP about his hoarse voice. He had never been prone to illness throughout his life and found the topic a difficult one. His introduction to the subject was "The dog behaved well in the Doctor's surgery today". As a matter of interest the dog is pictured on a walk at the start of the book. Little did I know that from that day on none of our lives would be quite the same again.

I know as I write these words that they will ring bells with many of you who have been down or are going down that same road with dearly loved family members. With the benefit of 29 years of hindsight I am able to say that despite the dangers and difficulties that he faced I am certain that my father would be intensely proud and almost unable to believe what the Charity has achieved both during his lifetime and since his death.

I am attaching a list of activities for the year ending in January 2008 so that nothing is missed. From shortly after his operation until quite literally the date of his death 15 years later my father dedicated his life (as did our mother Lucy) to the work of the Charity. To find that 29 years later people are prepared to jump out of aeroplanes, run 5 kilometres and even write a travel guide for the sake of laryngectomees would have delighted and intrigued him (he never was one for heights, running or travelling!). However, he would have recognised in each of the people who have taken part in these varied activities that same sense of purpose and dedication which kept him going in his utter determination to set up the Charity against considerable odds.

It is always a special day for me (as I know it is for Carole and Wendy) to receive one of those precious letters confirming that in some way large or small the Charity has been able to help someone. That is exactly what Syd was planning towards all those years ago.

I would like to thank everyone who has been prepared to support the Charity in any way during the year. As the Charity receives very little 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 2007 a net total of £2,616 was raised. Thank you for your support.

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

The Trustees would like to thank Keith Roper of Lambert Roper and Horsfield, Debbie Coates and the staff at HSBC, Nurse Michelle Beaumont, Nurse Carol Wise, John Bramall and Sovereign Healthcare

#### Activities during the year

- 1. On 16 February Carole Stainton visited the Wakefield support group run by Helen Chadwick to speak about the work of The Cancer Laryngectomee Trust.
- 2. On 4 May Carole Stainton represented The Cancer Laryngectomee Trust at a Laryngectomy Information Day for health professionals at Dewsbury Hospital, arranged by Helen Chadwick a Head & Neck Specialist Nurse from Pinderfields Hospital.
- 3. Summer lunches were held at Blackpool arranged by Malcolm Rothwell and 2 events at Bridlington by Wendy Thompson (May) and Ann Smith (July).
- 4. Fund raising by members and their families: Parachute jump by Rosa Taylor, the daughter of a member raised £742.50; Carole Stainton attended a presentation by Rosa Taylor in Burton-on-Trent which resulted in publicity in their local press; 5K race by Helen Trueman and Mandy, the sisters of a member raised £479.10 plus Gift Aid; Victoria Passingham, the daughter of a member sent £202 from a half marathon; The Video Dressage Competition run on our behalf by Judy Harwood raised £160 and has given us publicity to a very different group of people. A full list of all donations appears in the accounts.
- 5. On 16 October Wendy Thompson represented The Cancer Laryngectomee Trust at Regional Laryngectomy Support Day at York Hospital arranged by Val Cotter and spoke about the trust.
- 6. The Laryngectomee's Travel Guide to the British Isles has been prepared by member Paul Cantlie and is being published and distributed by The Cancer Laryngectomee Trust. It is proving extremely popular both

to laryngectomees and health professionals who are requesting bulk batches. A copy of the guide has been sent to a filtered selection of our mailing list of Health Professionals requesting that they provide updates if necessary. Once these have been received we need to run a new batch as the original 1,000 have almost all gone.

- 7. In the year ending 7 January 2007 we recruited 97 new members. This year we have had 151. All new members received a Welcome Pack containing rehabilitation items as requested. Part of the increase was due to the Travel Guide but many say Hospital as point of contact too.
- 8. Whenever possible Carole Stainton attends the meetings of Speak for th'Sen, the Kirklees and Calderdale head & neck cancer support group. On 16 November a joint meeting was hosted by Speak for th'Sen with Wakefield and Blackburn Larrys and health professionals attending also.
- 9. Christmas Lunches were financed by The Cancer Laryngectomee Trust in Halifax, Blackpool, Rotherham and Chesterfield. Wendy Thompson also attended the lunch held by York Laryngectomy Club.
- 10. The major fund-raising event was again Race Night 2007 with income of £4,227 gross and costs £1,611.
- 11. Three full newsletters and a brief Race Night results document have been sent to all members and to the Health Professionals on the mailing list.
- 12. 13 grant requests totalling £4,333 have been approved this year.

#### Ruth Kaye – Natural Healer

John Bramall Vice Chair of Speak for th'Sen reports:

Recently a group of members from the Calderdale and Huddersfield Support Group attended a meeting and talk given by Ruth Kaye who has worked as a Natural Healer in Leeds NHS for over 17 years helping cancer patients, their families, friends and the bereaved. Ruth's work is non denominational and she is a member of the National Association of Spiritual Healers – Holistic Healing practising since 1980 and is a former Samaritan. A brief

explanation of her work is to self empower through meditation using breathing exercises and benefits may include inner peace and strength, improved quality of life, relaxation, relief from pain, reassurance, ability to cope with stress and anxiety and improved sleep patterns.

It is understood that Ruth plans to hold another general meeting in Harrogate next March 2008. Meanwhile she now works from the New Cancer Wing of St James Hospital after moving from Cookridge Hospital. She also holds monthly meetings at the Britannia Hotel, Bramhope For more information please see her website: www.ruthkayehealer.co.uk

All the group members were very moved by Ruth's talk in September and there were long periods of quiet contemplation on the journey home afterwards.



Speak for th'Sen Members with Ruth Kaye centre

#### MedicAlert

For more than 40 years, MedicAlert has been providing a life-saving identification system for people with hidden medical conditions.

This takes the form of body-worn bracelets or necklets (known as Emblems) which carry the MedicAlert symbol as well as an Individual ID number and 24 hour emergency number. The emergency number is accessible in more than 100 languages and enables emergency personnel to access to Medical records in an emergency.

Chris Lunn from MedicAlert says:-

'There are now more than 280,000 members of MedicAlert in the UK who benefit from this service. We are very pleased to say that along with the traditional identification jewelery you can now purchase sportsbands, designer bracelets, necklets and also the MedicAlert watch. MedicAlert also works extremely hard to ensure that emergency personnel recognise the Emblem and are able to react accordingly in an emergency situation.

To find out more about MedicAlert and to join, please contact Tel. 0800 581 420 or visit www.medicalert.org.uk

## Getting Fit – Never Too Late?

Hello, my name is lain Price and I live in the West of Ireland. I am originally from Worcestershire but moved to County Mayo about eleven years ago. I asked the trust and others about running last year as I was approaching 40. I had my laryngectomy at 18, a long time ago, but had never really got fit again afterwards.

Bored with gyms which never did the trick for me in terms of losing weight, I decided to go running instead. I only managed a couple of miles the first time, walking some of it, but I was fitter than I thought and enjoyed the experience. Why hadn't I done this earlier I thought?

Well in truth, I know the answer – I didn't think I could. Even when the running was going well I approached the trust and tried to find out if I was doing something I shouldn't and what problems I may encounter as

a laryngectomee. But there are none – or at least none that anybody else trying to get fit would not face. So I entered a half marathon!

I raised some money for The Irish Cancer Society (the Laryngectomy Association of Ireland part of it in particular, 770 Euro in total) which put pressure on me to complete the event. It was the Connemara Half Marathon in April 2007, which was local but a bit of a tough one to pick for my first race. The hill called "The Hell of the West" on the route was aptly named, but I got over it and finished just a few seconds over the 2 hour mark. In the summer I then got a few minutes the other side of the 2 hours in the Achill Half Marathon, but I didn't stop there...

Aware that I may not be as fit again and that winter in County Mayo would offer little training opportunity, I decided I would try a marathon. I plumped for the Anglesey Marathon in September. This also proved to be a little hilly and I seem to be



lain at the Achill half marathon with children James and Sinead.

unable to find flat runs to do. However, the incentive of missing the ferry back to Ireland if I didn't finish the course got me through. Half way around in 2 hours as per my normal pace, I eventually finished in 4 hours and 26 minutes exactly. I was very pleased with myself though and had time for a few celebratory pints and some fish and chips in Holyhead before my return journey. Unfortunately I had to travel on my own for that one as my wife could not get away from farm and child duties. However, the whole clan will be with me in Cork in June to attempt my second marathon there. Yes, Cork is also hilly...

Before that I am warming up with my second Connemara Half Marathon again this April.



lain relaxing at Christmas with wife Caroline and children. The "Hell of the West" holds no fears for me now. So I hope any laryngectomee reading this who wonders whether they can or should get active again will give it a go, as long as that's okay with your doctor!

Since moving to my wife's county in Ireland, under her tutelage I have also become a bit of a cattle farmer and I even found time to write a children's book, published in 2005. It is probably only known well in County Mayo, but if anyone is interested it can still be got from www.amazon.co.uk or ordered from any book shop. It is called "Johnny the Pookie" and I thought I might as well plug it here whilst writing my running article!

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



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