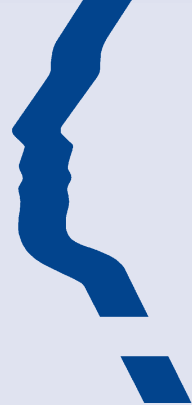


CLAN



THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS NEWSLETTER

Issue No. 126

September 2013

Inside this issue

A Good Turn-Out in the North ... 2
Ivor The Educator 3

BAHNON 3
Andy Gage - CLAN Profile 4-5
Message in a Bottle 5
Chocolate Beetroot Cake 5

A Laryngectomee's Humour 6
News from the Clubs 7-8
Plus lots of other news, thoughts,
poems, letters and views



**Rosetta Eileen
Hayes**

6 August 1927 – 19 June 2013

One of NALC's first Lady Vice Presidents Rosetta Hayes has died. Rosetta was a member of the Amersham Club from 1993. She became Secretary of the club in 1994 and was a regular member of the General Committee until she retired in July 2012.

Rosetta became NALC's Vice President in 1997 and served in that role until 2003. She was a regular on our Patient Panels along with her husband Jim and was also a member of the team that produced the Living with a Pharyngo-Laryngo-Oesophagectomy booklet.

Rosetta was a lovely lady and an inspiration to all that knew her, she will be sadly missed



A WORD FROM THE EDITOR

WHAT A SUMMER!



We hope you all had a very enjoyable – and amazingly warm – summer! The Editor and Mrs Editor took the opportunity for another cruise – to Iceland. *En route* we visited the Giants' Causeway (fascinating), Skye, St Kilda and the Faroes (on the return). In all we circumnavigated the realm. What sights! We climbed a volcano (inactive), saw waterfalls, geysers and bubbling mud pools. Even came face to face (but no direct contact) with an iceberg. Highly recommended if you've never been there (Iceland, not the iceberg).

BUSY, BUSY

We didn't bump into any more laryngectomees this time though. And talking of bumps – we've a 'bumper' issue with what we hope is the first of a series of Profiles about the NALC Officers who do such a great job. Andy Gage, NALC Vice-President and Webmaster, bravely agreed to go first. We also feature Ivor Smith who's as busy as ever educating and entertaining First Responder groups who are first on the scene of accidents. And lots about the very successful NALC Conference for Scotland and the North of England. As for the Editor's family, all attention is now on our daughter's wedding in September. Start praying the good weather continues...

Ian Honeysett
Ian Honeysett (Editor)

Annual Lunch

The NALC Annual Lunch on Sunday 1st September was held at The Royal York Hotel, York.

The menu included roast peppered topside of beef, baked salmon and wild mushroom risotto.

For all items for *Clan*:

Ian Honeysett (Editor), 53 Combe Road, Farncombe, Godalming, Surrey GU7 3SL
email: Honeysett@btinternet.com

For all other matters (including requests to be added to or removed from the mailing list):

Vivien Reed (Association Secretary), NALC, Lower Ground Floor, 152 Buckingham Palace Road, London SW1W 9TR Tel: 020 7730 8585 Fax: 020 7730 8584 Website: www.laryngectomy.org.uk

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Deadline for issue No. 127: 1 November 2013

A Good Turn-Out in the North

Anyone walking in from Glasgow's Grand Central Station into the Grand Central Hotel's foyer on the morning of 25 June could have been forgiven for thinking that the hotel had been taken over by laryngectomees! And they'd be partially right. For this year's Scottish & Northern Laryngectomee Clubs Meeting was taking place in one of the hotel's many Conference suites, and with 'standing room only' for part of the time.

New Products...

Taking time to visit the many Supplier's Stands was well worth it at the start, as reps from many of the major laryngectomee equipment companies were there, including Forth Medical, Kapitex, Platon, Insight Medical Products and Insight Technologies, with new products to show, like the new Blom-Singer Dual Valve, and the Provox Vega voice prostheses, and other advanced equipment.

Busy Agenda

The main proceedings started with a Welcome from Ivor Smith, a Vice President of NALC, and then Andy Gage, another Vice President, and also NALC's Webmaster, talked about how the Website (currently getting over 100 visits a week) is the online 'voice' of NALC, for news and announcements. One of these – to be published shortly – could herald a major breakthrough in laryngectomy surgery and treatment, and change the outcome of newly-diagnosed larynx cancer patients with a 'new dawn' of advanced treatments.

Potential Laryngectomy Breakthrough...

This has all come about through a 2.8million Award granted to one of NALC's most respected Patrons, Professor Martin Birchall, chair of Laryngology, and his research team at the UCL Ear Institute, and the Royal National Throat, Nose and Ear Hospital. The Award will go towards a research project called RegenVOX, involving the preparation of a reconstructed larynx, made from the patient's own stem cells, plus a donor larynx. Chemicals will remove the cells from the donor larynx, leaving a 'shell' on which the stem cells from the recipient can be grafted, thus bi-passing the common rejection problems normally associated with other transplants – and enabling the formation of a new larynx.



Instead of the current laryngectomy post-op problems – which generally involve speech, breathing and swallowing problems, and little taste and/or smell left – these could be a thing of the past. The possibility of giving newly-diagnosed laryngectomee patients their voice, smell and other functions back, and re-convene their pre-op quality of life, is extremely exciting. And it could be done on the NHS too!

Watch www.laryngectomee.org.uk for further news...

Professor Birchall plans to start the first transplants in a year's time, with ten new patients, and these will be monitored over two years to prove the safety of the work. More details coming shortly – to be published on the NALC Website.

More Agenda News...

Following the above announcement, it was Macmillan's turn, with Alan Gow, Macmillan's Involvement Coordinator, talking about the work Macmillan is involved in at present, including helping cancer patients experience better treatment, and clinicians a greater understanding of an individual's care and wellbeing needs, in hospitals across the UK. Other projects involve enabling patients to have 'a greater say' in their treatment in general, by expanding the Patient Experience Committee groups in many areas, and helping with research projects, where possible.

The Benefits Question and Fire & Safety...

Amanda Gallagher, an experienced Benefits adviser, spoke about the new UK

Government legislation affecting many of us at present, with the changes to the Disability Allowance, and the new 'PIPS' coming in, with new criteria for the under 65s (different rules apply in Scotland). Amanda explained some of the ins and outs of the new system, how and where to get help, and what one might expect to happen, and afterwards arranged to speak with individual delegates wanting more info.

Fire and Safety was handled by some great Scottish Fire Officers, including their leader, Ian Thomson, who together told some hair-raising – and some hilarious – stories involving how fires can start, and what can happen in fires, and how to be extra vigilant in your home, with electric and gas appliances (and barbecues, etc.) and gave some valuable advice that could save lives in an emergency.

The Throat Cancer Association...

Next, Ewan Lumsden, Digital Content Manager, gave us an update on the Throat Cancer Foundation (TCF) which was founded in 2012 by Jamie Rae, a Scottish businessman and oropharyngeal cancer survivor, who was concerned at the lack of resources and support available to people affected by cancers of the throat. Today, TCF is dedicated to continuing to provide this support, and offers information, support and community to all those who are affected, both patients and their loved ones.

Research into reducing future throat cancer cases...

Jamie has recruited a team of leading cancer experts to guide and support our

work. Have a look at our team page to see some of our supporters. This includes funding research into prevention and cure, advocating healthier lifestyles and campaigning for universal HPV vaccination. 'HPV' stands for Human Papillomavirus Virus, which lives in the skin, and can be treated with a vaccine. Have a look at TCF's HPV and campaigning sections for more information about their work to try and prevent cases of throat cancer.

The turn of the Clubs

Brief presentations from attending NALC Club Committee Members included one from Ann Muir, Information and Support Officer at the Speak Easy Cancer Support Group. This Lanarkshire Club represents laryngectomees and various different cancer patients, and is involved with helping to inform people about getting benefits and allowances; also research into patient care, and laryngectomee issues. The Club is also involved with Macmillan Cancer Support, dealing with Insurance for laryngectomees, and has also succeeded in gaining many Fundraising Awards to help with their work. Visit their website at www.speakeasylaryngectomee.co.uk for further details. Other Clubs reporting included the Central London Laryngectomee Club, chaired by Andy Gage.

Manufacturers, Lunch & Raffle...

Finalising a very busy but productive morning, the various laryngectomee equipment companies gave brief presentations of their products (see 'New Products' above) which were all available to study and get further details on, in the

well-stocked display stands in the Suppliers' area.

There followed a fantastic spread of lunch sandwiches, salads and other goodies, and the Grand Raffle, organised by Vivien and Kerry from NALC's Head Office, which – as usual – offered a glittering array of useful prizes to win.

All in all, a busy, well attended day, with lots to take in, learn from, and enjoy. As we all slowly departed from the palatial surroundings of the Grand Central Hotel, the nearby Rail Station was filling up with Police and Security Guards – I thought, there to give us all a 'Grand' send-off – but no; they were awaiting the imminent arrival of Robby Williams!

The British Association of Head and Neck Oncology Nurses

(BAHNON) held its biennial conference in Manchester on 14 June. NALC president, Malcolm Babb, and Vice-President Ivor Smith attended the event and manned a stall to advertise our work and distribute examples of our publications. As at the previous conference in Cardiff, the stall proved very popular and, by the end of the day all the leaflets, DVDs and other materials had been given out.



These specialist nurses do a wonderful job and NALC is pleased to be able to help them by supplying patient information and other resources to assist laryngectomees on their journey to recovery.

Malcolm Babb

Ivor the Educator

Cumbria is a very rural area and a lot of the villages and outlying areas have set up first responder groups. As they are based in the community, they frequently arrive at an emergency well before the Ambulance Service, carrying vital emergency equipment as well as being fully trained in first aid. They are a valuable asset to the Ambulance Service and the community in general.

When Ivor Smith, an NALC Vice President and himself a Cumbrian, was asked to give one of NALC's educational talks to the First Response groups, he was more than happy to oblige.

So on a very warm August evening about 40 First Responders (as the groups can

be quite small the First Responder group who had organised the talk had invited three other groups from the local area to attend the talk as well) were crammed into a very stuffy village hall to listen to Ivor deliver his NALC education talk. Despite the heat, Ivor was pleased that so many attended and were given the opportunity to learn about the needs of a laryngectomee in an emergency situation should they come to the aid of a laryngectomee in the future in their role as a First Responder.

About ten of the people admitted that they had attended Ivor's talk before and felt it was worth coming along again, not only to refresh their understanding of a laryngectomee but also for the entertainment! Ivor promised them he

20-20

The '20-20 Voice' Cancer Appeal have now purchased a number of printed T-shirts which are on sale at £10 each (inc p&p) Happily, having bartered with the supplier, they are able to make a small profit on each T-shirt sold. T-shirts are a great way of spreading the word and creating the much needed awareness. They have them in Small, Medium, Large and XL and if anyone wants to support the cause either contact Phil Johnson through admin@2020cancerappeal.org or telephone him on 0116 2997760.



*John Kennedy
our Triathlon hero!*

On 27 July, John Kennedy, a 20-20 supporter, went off to London to raise funds for 20-20 by taking part in the London Triathlon. On what was a sweltering day in the capital (John said the humidity was horrendous), he managed to complete the course. Many struggled so this is some achievement! The Triathlon comprised a 400 metre swim, a 2.5 km run and then a 10 km bike ride! It looks like he raised nearly £400 for the Appeal and it's rumoured his employer (Network Rail) will be matching this amount. A nice bonus for the charity.



would have some new jokes for the next talk.

At the end of the talk, the Chairperson, who had organised the evening, thanked Ivor for what he said had been a very informative talk and a most entertaining night.

Andy Gage – CLAN Profile

Andy Gage, Writer, Webmaster, Horse-lover, Laryngectomee and a Vice President of NALC

I moved back to my 'roots' – in Norfolk; the land of my 'fore-fathers' – nearly four years ago (but more about that later). For over 40 years I had lived in London, starting in Earls Court, just down the road from the then-famous Café Des Artistes, one of the Rolling Stones first Club venues off the Fulham Road. I was a 20-year old ex-Art Student, sharing with five other friends, and it was the mid 60s... what a time we had!

I then 'graduated' to a flat with a girlfriend off Kensington High Street (much to the annoyance of my late mother, who lived in Sevenoaks, Kent, where I had part of my childhood). I then married a BBC Vision Mixer (I was getting established as an Ad Agency Copywriter at the time, and she was moving up in the BBC) and we lived in a flat in Maida Vale, for a while...

Our first 'Home on the Hill'...

We had a hankering to get back into central London again, and as our careers progressed (I was working for Reader's Digest in Berkeley Square by then, and hopping over to the New York office on occasion) we managed to buy our first 'real' home in Notting Hill (which had survived the riots, and was fast becoming 'gentrified' by then).

We had many glorious years there, in a garden flat, and then in a small but beautiful old Railwayman's Cottage in a secluded Mews off Chepstow Road. This was the 'arty' side of Notting Hill, with Tom Baker (an original Doctor Who) and other now-famous artists and actors living just round the corner.

Sadly, after a roller-coaster, 'hi life' with my then wife, jetting off all over the world for various BBC outside broadcasts (including the Moscow Olympics) and me working almost 24/7 as a Copy Chief in a top London Ad Agency, we parted. I stayed in Notting Hill, she went to Richmond Hill, overlooking the Thames.

My second 'Hill Home'

I eventually got married again, to the then Principal of a large London College of FE – who lived in Crouch End (before it came a Media Village)! It was too suburban for me after Notting Hill so, with some persuasion, I moved us to Muswell Hill,

near Highgate Woods, spent a year doing up our big, lovely old rambling Edwardian house... and then had our first and only child, Oliver. These were busy times, filled with au-pairs, nursery pick-ups and – I was running my own Copywriting and Design Business, partly from home, and also from my Design Partner's Studio in Barnes, SW London.

After a spell in the local Primary, Oliver astounded us all by getting a place at Highgate School. There he blossomed in Maths, Cricket, and Music for a while, and Languages. He left the 6th Form with excellent 'A' and 'A*' grades, and is now reading Maths and Philosophy at The University of Sheffield.

Then came the 'Double Whammy'...

My business was going from strength to strength, working with top-line Publishing, Catalogue and Marketing clients, and competing with the Ad Agencies I once worked in, and this continued for over 11 years. But the more successful my company 'Creative Solutions' became, the more I, and my Design Partner, smoked. For the last three years of our working together, my throat was becoming gradually more and more croaky. (Luckily, his wasn't.)

It was also becoming obvious that the recession was taking hold. Our clients were faltering, and then, almost overnight, three of our largest client companies announced they were shedding 50% of their staff, taking all their copy and design work in-house, and therefore stopping using us (or any others) for creative work. By that time, my throat was becoming worrying... and business debts were mounting, and I had to put my house on the market (we had split our family house by then).

After many trips to my local GP, who didn't suspect anything bad, things worsened, and I was eventually referred to UCLH. After two biopsies there, I was told the 'c' news and advised to have a laryngectomy...

Dark Days... with a Silver Lining...

With the recession worsening, and living with a colleague at the time, I entered Ward T14 at UCLH with not a lot to lose.



Luckily, after a successful operation, I discovered (with the help of the amazing team of Speech and Language Therapists (SLTs) I could speak fairly well after a while, with a voice-valve in place. I also met many other laryngectomees in the same ward – all from different walks of life, and sharing the same early post-op frustrations of tube-feeding, and having to write everything down, but our slow improvements in verbal communication gave me hope that things could get better. There were also a few humorous incidents, which took our minds off the reality of it all. I think all laryngectomees are in denial in the beginning.

New Beginnings, new Career...

My first year as a laryngectomee was a learning process... getting congratulated as a survivor by good friends was gratifying, getting my son used to it was a longer process (he was in the middle of his last Highgate exams at the time). But being accepted by new friends quicker than I thought was good. My 'secret' was not to be self-conscious about the hole in my throat, or having to hold my stoma button to speak.

My greatest asset was my ability as a writer (after 30 years as a copywriter, I would hope so!). Being of a positive nature, I also became involved with the workings of UCL Hospital and Macmillan and its Patient Committees, and NALC, and the possibilities open to all laryngectomees, if they go out and grab them.

I applied to join the Macmillan Patient Experience Board, and was accepted on to the Committee, and became Lead for the Written Information Improvement team, working with Managers, Directors and Clinicians, and a great team of ex-professionals, who had all experienced various forms of cancer. This was the beginning of my (non-paid) new career.

NALC was often promoted at UCLH, with leaflets and details for all laryngectomee patients and I was encouraged to go to their general meetings, and meet with other laryngectomees from all over the UK. I quickly realised that NALC was unique in the beneficial work they did across the country, with almost 100 clubs nationwide and a range of services, including an extensive Educational Programme, delivered to health professionals, medical students, and Ambulance personnel. NALC's remit is to publicise the problems of laryngectomees, and those of their families, and to encourage understanding – both of medics delivering emergency treatments, and by the general public – as to their needs and well-being.

My move – to another Hill...

As I said, my 'roots' were in Norfolk. As I had sold my London house, effectively closed my main business, reached 'retirement' age (writers NEVER actually retire) and my son had left for University, I decided it was time to go back to Norfolk, and live a slightly 'softer' life away from London. All my family on my mother's side were either Norfolk farmers and landowners, or teachers. (Sadly, my father – who was an American Naval Captain – died at the end of the war, and so was never able to return to enjoy the post-war years in Norfolk, with my mother).

But I had idyllic summers and winter school holidays on my uncle's farm near Swaffham, mid Norfolk, surrounded by horses, riding my own pony, driving tractors, going hunting and loving farm life. I now live in Holt, a historic Market Town – on a slight hill - in North Norfolk, only a few miles away from my grandfather's and uncle's original farms. (Funny, but it seems more Norfolk people know about laryngectomees than Londoners.)

Laryngectomee Clubs ...

Although firmly rooted in Norfolk life now, where I'm writing Websites, and Macmillan Editorial work, and E-Book projects – and working with RDA North Norfolk, helping local disabled children to gain confidence by riding (which means I also get to be with horses again!) – I travel to London almost every week, for Macmillan Committee Meetings, Cancer Project group work, and NALC Meetings every two months or so. I became involved in the NALC Website because of

my writing/web experience, and was recently honoured by being voted on to the NALC Committee as a Vice President, as well as Webmaster. I'm also Chair of the Central London Laryngectomee Club, which started up just over a year ago, and is connected to UCLH, and based at the Macmillan Cancer Centre.

As well as handling most of the content on the NALC Website, as a Vice Chair, I also attend their Committee-only Meetings, plus the recent AGM in London, and regional Meetings (incl. the June Northern & Scottish Day in Glasgow) and often present laryngectomee news and updates to the member audiences (see www.laryngectomy.org.uk).

As well as being a place where local members can get together and feel supported, the most established clubs also have an active group of members, many with a central theme of supporting a local charity and/or campaigns to improve the laryngectomee cause, nationwide. (As my mother used to say 'The more you put into something, the more you get out of it'...)

'Things can only get better...'

As the song goes, right now, it's coming up to an exciting time in breakthrough research into stem-cell and transplant surgery and new laryngectomy treatments. New £multi-million grants are speeding up this pioneering work right now, and the future looks bright for new pre-op laryngectomees... (read more about this at www.laryngectomy.org.uk). In another few years, established laryngectomees may also benefit.

Onwards and Upwards...

These are also exciting times for NALC, and the clubs. With computer, mobile and internet systems getting cheaper and easier to use, the possibility of greater support and information communication can only make things better. I can see NALC expanding its existing support systems and maybe going into new beneficial laryngectomee equipment design and development, as well as other innovative projects to benefit all new, and established laryngectomees.

As a writer and webmaster, I'll be making sure that all our NALC laryngectomee readers are the first people to know about – and get more out of – the latest news..!

(So keep watching
www.laryngectomy.org.uk –
and reading CLAN – of course!)

Message in a Bottle

A recent CLAN insert was a leaflet on how to access the "message in a bottle" scheme. Well, reader Brenda Loynds contacted them and Alan J. Hastry, from Oldham Lions, promptly replied and sent her 12 bottles to allocate to members of the New Speakers' Club.

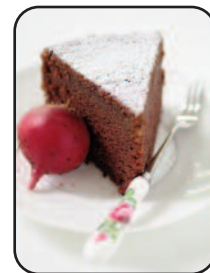
The photo shows Lion President, Marjorie Hastry, presenting them to her. The Lions Message in a Bottle scheme is a simple idea designed to encourage people to keep their personal and medical details on a standard form and in a common location – the fridge. (For more information see: www.lionsmd105.org)



Chocolate Beetroot Cake

Ingredients

2 tbspcocoa powder
4 oz plain flour
½ tsp baking powder
Pinch of salt
5 oz caster sugar
8 fl oz corn oil
1 tsp vanilla essence
3 eggs – beaten
7 oz plain cooked and grated beetroot (not beetroot in vinegar!)



Method

Preheat oven to 190C/375F or Gas 5. Grease and line a 7 inch round cake tin. Sift cocoa, flour, baking powder and salt into a large bowl. Mix in the sugar, followed by all the other ingredients and mix well. Pour the mixture into the prepared tin. Bake for 50 minutes – the middle of the cake should still be sticky. Turn out and cool on a rack. Serve with cream or custard.

Ian & Rose Browse

Taken from *Soups & Puddings* produced by THANCS Group. Minimum donation (from non-laryngectomees) of £2.00 per copy. THANCS group: Hawthorn Suite, Worcestershire Royal Hospital, Charles Hastings Way, Worcester WR5 1DD.

A Laryngectomee's Humour

I have been a laryngectomee for nine years now, and at our club meetings, held in private room at our local hospital, there are always four or five nurses present from the ENT wards, and of course we know them all being friends, but my colleague 'Larry's', delight in making them roar with laughter, whilst keeping a straight face, and saying something that could have been written as a comedy film or TV script. We seem to delight in making people laugh. I thought about this and I am just as guilty, but I am mischievous in a nice sort of way, rather like an innocent child saying something out of place.

For example, when I had my pacemaker replacement, I had to stay awake to control my breathing, and was chatting to the two doctors, nurses and technicians as it was being performed. There were slight problems and it took just over an hour and, as they cleaned up, I sat on the operating table, with my feet dangling, waiting for my bed to be wheeled in, when I said, "Can I have your attention?" They all stopped and looked at me, and I said, "I just want to thank you all for doing a first class job. Have any of you ever thought of doing this for a living?" After a stunned silence, they all burst out laughing. Not the usual sounds in an operating room!

I have had eight operations in my local hospital over the years having parts replaced and know that trainee surgeons are in attendance on most occasions and suspect that they be given the task of some part of it. In my usual mischievous style, before I go down all prepared, I pin to the operating gown, this note:

*"PLEASE TAKE THE UTMOST CARE"
Surgeons must be very careful,
when they take the knife,
as just beneath their fine incisions,
lurks that culprit 'Life.'*

Seminars

Again when helping out at Seminars, with an audience of general practice doctors, dentists and nurses, I always ask if there are any German people present, as the Blom-Singer valve was invented by two German doctors who now live in America, and is a marvellous thing, enabling many thousands to speak again. Then I say in a very serious voice, "But it does have setbacks, the most important is that I tend to swear in German." The audience erupt with laughter and from that moment on

you really have their attention. I often wonder why we laryngectomees have this innate sense of humour, and love to hear people laugh out loud. Maybe it's because that is something we cannot do ourselves, but in our own strange way love to create that sound in others.

I am sure some psychiatrist would have the answer.

Knowing the Drill

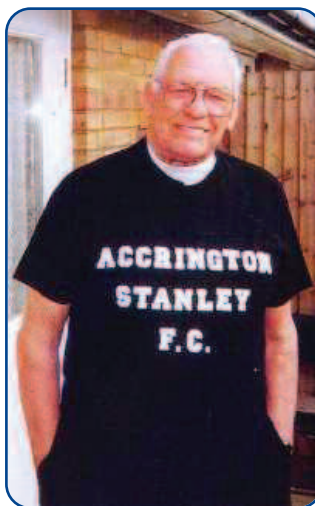
I remember going to a supermarket, and because of the queues, I went to the do it yourself check-out, but the robotic lady's voice was not working, but knowing the drill, I went through the procedure. As I left I stopped by the young girl assistant standing there waiting to help customers, and told her the voice on my machine had stopped working. She smiled sweetly and said, "Yes I know, sir." I said, "I go to that machine nearly every day, and your machine's robotic voice has become friendly with my robotic voice. Now today, she hadn't said a word. Could you find out if he has upset her in some way, and said something out of place." Her face was a picture and her mouth dropped open as she tried to assimilate all that nonsense. Then she saw the twinkle in my eye and burst out laughing. As I left the store with a smile on my face, I had a fit of coughing to clear the trachea, and I thought, "These darned aches, pains and medical troubles are never far from us." As I drove home, I thought of one of my poems which fitted perfectly.

The Pretence

The mask we wear, that smiles and lies,
so hides the tear that's in our eyes.
We practise hard with inner guile,
with torn and bleeding heart, we smile.

Why should we show them otherwise,
why should we let them hear our sighs?
Let them not think, or dare to ask,
That this our smile is just a mask.

Len A. Hynds



The Lothian Laryngectomy Group

The club has been going for almost 35 years and, after meeting in various homes, are now based at Maggie's Cancer Centre at WGH, Edinburgh where they meet every month. They usually have between 15 and 18 members who attend most meetings as well as other members who come along as and when they are able.



Since their first group weekend away in 2011 when they went to Garve in the Highlands which was a great success, they have been to Braemar in 2012 and this year in May they went to Dunoon and are due to go to Blackpool in October for the week-end. Everybody agrees that these weekends are very important to the group and it is good to be with like-minded people who understand their needs and requirements. These weekends away have been possible by their fund raising. For some people it might be the first time that they have been away since having their surgery and because they have a whole weekend, they have plenty of time to compare notes and experiences. Usually the Lary Group are last to go to bed as they are so busy sorting out the world. It has given them time to bond as a group which they don't necessarily manage at group meetings when they have speakers and business to deal with.

They were also able to buy Press Don't Panic alarms for new members and donated some to St John's Hospital, Livingston for any patients who required them.

continued on page 8



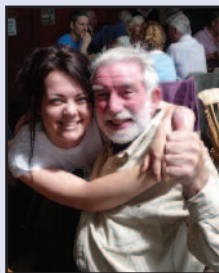
News from the Clubs

Ashford Laryngectomee Club

They enjoyed a summer outing on the Romney Hythe Railway, enjoying a scenic ride through the Kent countryside to Dungeness. We then enjoyed a lovely lunch at The Britannia Inn where the food was lovely and staff very warm and accommodating. As you can see from some of the photos, club member Caroline Mackenzie's daughter comes along and ensures that all club members are well looked after. Their July outing was to DePanne and Ostend – so as you can see they are a very active support group. The club was



awarded the gold award from the Mouth Cancer Foundation earlier this year for the support they provide as well as the work they do to raise awareness.



Lanarkshire

The club has succeeded in gaining many Fundraising Awards to help with their work. Plus they've recently held a fundraising walk which raised £1,500... and been nominated for the Queen's Award for Volunteering in a Community Setting. Visit their Website at www.speakeasylaryngectomee.co.uk for further details, including a helpful section on answers to many questions about laryngectomy in general.

The Plymouth Laryngectomee Club

The club, as ever, has a full programme of events. In June, they had an outing to Buckfast Abbey. Six of them went and were joined by three friends from Newton Abbot. The Abbey is in a beautiful setting and, although the buildings were being worked on by stonemasons, this didn't detract from their enjoyment. A light lunch then back home. In August they enjoyed a cream tea at the Knightstone Tea Rooms near Yelverton. In September it's the NALC Lunch in York.

The club has decided not to keep its website updated but to focus on its Facebook page instead. You can see that at: www.facebook.com/pages/Plymouth-Laryngectomy-Club/111621182271959?hc_location=timeline

The Mustard Tree Cancer Support Centre, Plymouth (where the PLC meets) ran a series of workshops in July for cancer patients, family and carers which gave an opportunity to learn and talk about life with a cancer experience and navigate a way through diagnosis, tests, treatment and living well. The topics included: Identifying stress, learning to relax; Radiotherapy: coping with side effects and keeping healthy; Planning a future with confidence; Asking questions and getting help: communicating how you are feeling; and managing fatigue.

On 25 October, the Speech and Language Therapists in Cornwall, Plymouth, Torbay and Exeter are hoping to run an 'Alternative Laryngectomy Day' in the Mustard Tree Cancer Support Unit at Derriford Hospital starting at 12.30pm. It's hoped the PLC AGM will take place an hour earlier.

Lost Chord Club, North Staffordshire

The photos show members having lunch on 8 April which was attended by 26 people.

They also show the presentation of a cheque by Mr and Mrs David Sigley to Bernard, Sam and Elizabeth who received it on behalf of the club. Beryl Sigley and



her friend Kate run a stall at the old Price and Kensington Factory at Longport table top sale every Wednesday and Saturday 8.30am to 1pm to raise funds for the club. Their donations have enabled the club to purchase five Nebuliers, one DVD player for Staffordshire University Hospital and communication aids for Stafford Hospital. All for the benefit of laryngectomees.



Speak Easy Club, Cornwall

In June they joined the Recovery Club at The Queens Arms, Botallack, St Just. A bit like a step back in time – it's such a lovely example of an old Cornish village and there was no electricity as they walked into the candlelit pub. The power cut affected the entire area so they sat and chatted until the lights went on and lunch could be prepared. A raffle followed, then an auction of the now famous tin of Spam, which Ron bought, so no doubt it will have an outing at their Christmas party! Then Brian led them on a walk to the remains of beautiful arches and mine buildings. They

could hear the sea below but the sea fog had closed in, giving them a vague idea of how tough conditions must have been for the workers. In July they visited Melinsey Mill. The sixteenth century Mill was well worth a visit – Pat & Peter, Val & Nigel, Janet & Jan were joined by Chris & Dave from the Recovery Club. After lunch (all home made), a look round the mill workings and ancient equipment, a chance to buy local produce and crafts, followed by a leisurely walk around the delightful wild lake, with twists and turns revealing quirky surprises.

News from the Clubs

The Windpipers, Blackpool

Their July trip was to Skipton & Keighley and the Worth Valley Railway. Member Ginny Williams' husband, Mike, was doing the Manchester to Blackpool bike ride. And their wine raffle raised £16. They report that the Cancer Laryngectomee Trust Lunch at The Savoy was a great success and the Windpipers decided to donate £100 towards the Trust for all the good work they do.



Then one of their members, Ginny Williams, her husband Tony and Ginny's son (who is an A&E Consultant at Preston Royal Infirmary) entered the Manchester to Blackpool Bike ride on 14 July 2013 and both completed the race and received their certificates, Tony raised £166.50 which he kindly donated to The Windpipers. The group would like to say a big thank you and his wife Ginny is very proud of him and her son for their achievement. Tony is the one holding the certificate.

Oxford Club

The Speech Therapy Team of the Blenheim Head and Neck Unit at the Churchill Hospital in Oxford invited members of the Oxford Laryngectomee Club and other laryngectomees who had their operations some time ago to take tea and cake together to celebrate the unit joining the rest of the cancer units in one place. The Head and Neck unit had been a few miles away in the John Radcliffe Hospital until March. It was also a chance for the Speech Therapy Team to highlight how important the support and experience of old larys is to new patients.

To illustrate that, Bob Wingrove from the OLC and Tony Hudson from Amersham and Chiltern Chatterbox Club and their wives spent some time with two new laryngectomees and their carers to answer their questions and talk about some of the equipment available to them.

Members of the Wiley family were also there as recognition of the great effort Ken Wiley and others had made for the Oxford Club and in fighting to get the Head and Neck unit moved to the Churchill Hospital. Penny White, one of the Speech Therapists, gave a welcome to everyone and noted how 'noisy' it was for a group of people without vocal chords!

On 21 July the Oxford Club held their annual summer lunch at the Littlebury Hotel in Bicester. 53 people attended and had a very enjoyable time, and due to the beautiful weather made full use of the gardens. A raffle was run and £250 was

Leicester Club

Wednesday 26 June saw the 30th Anniversary of the Leicester Larys club and 17 members converged on the White Horse Public House for a celebration dinner, which was enjoyed by all. Sadly, Phil Johnson missed it due to a chest infection. One of their supporters, Sarah Lightman, took on the Isle of Man '17 Parishes' Walk on 22 June. The event is a horrendous footslog around the 17 spires on the Isle of Man, totalling 84 miles which Sarah completed in an incredible (non stop) 20hrs:04mins:18secs to finish in 67th position. Considering she is no *bona fide* walking enthusiast, this was a tremendous effort, even more so after finding out that the crew camped out on the island – no comfy beds before the trek! Not content with that little jaunt, Sarah also booked in for the '20-20 Voice' bike ride from Leicester–Skegness on 17 August! '20-20 Voice' sure have got some girl-power this year!



made for the club funds.

Great thanks must go to Gordon and Carol Vacher who did the organising and running around as they do for all of the Oxford Club events.

The club meets on the second Saturday bi-monthly, and the next meeting is 14 September at the Littlebury Hotel Bicester at 2pm.

Central London Laryngectomee Club

The club, chaired by Andy Gage, celebrated its first anniversary this month, and has a list of 28 members, and so far has held six meetings. The club continues to be supported by Macmillan/UCLH and its Admin and SLT staff, in Euston Road, Central London, and is still fortunate in being able to hold regular meetings in the 'State-of-the-Art' UCH/Macmillan Cancer Centre, near to UCLH in Huntley Street, WC1E 6AG. Recent meetings have included talks by fundraising experts, also from Henrietta Spalding, Head of Policy & Practice at 'Changing Faces' – a charity helping people to cope with managing physical and speech differences in society. Presentations have included demonstrations from various laryngectomee equipment supplies company managers on new beneficial products coming out shortly.

Having been successful in being chosen as one of two favoured charities to receive sponsorship from the '23 Mile Running Club' (a Marathon Running Team) to benefit from sponsorship at the recent London Marathon, pledge collections are likely to top a good 4-figure sum, which will be shared by the laryngectomee club, and a children's home charity in Africa. Meanwhile, outside club events have included a 'Family Festival' and picnic on Hampstead Heath, and now, concert/theatre outings may be in the pipeline.

The Lothian Laryngectomy Group

Continued from page 6

Among their various speakers this year, they have had Maggie's Benefits Adviser and two of their Speech Therapists and are looking forward to a visit from local radio presenter Grant Stott in September who is also a great favourite in the pantomime here in Edinburgh.

Their fund raising events include Sponsored Walk which raised £1,126 this year and a Christmas Raffle which last year brought in £910. They have planned for later in the year the Christmas Raffle, Christmas Party and Pantomime and, at the turn of the year, they have their Annual Lunch at the City Restaurant here in Edinburgh (worth a visit if you are ever in Edinburgh.)