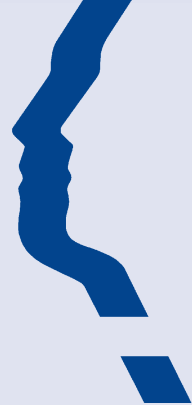


CLAN



THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS NEWSLETTER

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THE FUTURE OF NALC

WE NEED YOUR HELP

NALC is grateful for generous financial support for over 30 years from Macmillan Cancer Support, which has provided for the bulk of our funding needs. Now Macmillan wishes to reduce this support over the next few years, with the goal of NALC becoming financially self-sufficient. Macmillan will be continuing to support NALC in a variety of ways during this transition. An action plan has been agreed with them to help NALC become an independent and self-sustaining group.

Many changes will be needed to adapt to the new situation. Previously we have not had to run fundraising campaigns or seek donations. Any potential donors have been advised to give money directly to Macmillan and not NALC itself. The Officers and General Committee of NALC have little experience in this area but are determined to adapt to this new situation. We will be working very hard to ensure we can continue to provide all of the services that NALC has delivered to patients, carers and clinicians and make sure the needs of the laryngectomee continue to be met.

What does NALC do?

We are using *CLAN*, our website and letters to individual clubs to make sure that every one who is part of or involved with the laryngectomee community is aware of our new situation and also the range of services we deliver. On page 3 you will see the full details of our work, some of which you may not be familiar with. I also commend the article on the Education Programme on page 5, which is a developing and important part of our work.

How You Can Help

We are also launching an appeal to all the members of our clubs and readers of *CLAN* to support us in this challenging period. You will find many suggestions for how you can do this and how to get involved on page 8. In the next few months there will be further information on the website and in future editions of *CLAN* about what we will be doing and how you can help.

PLEASE GET INVOLVED TO ENSURE LARYNGECTOMEES WILL CONTINUE TO BENEFIT FROM THE SUPPORT THAT NALC PROVIDES

Malcolm Babb

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The views expressed by the contributors are not necessarily those of the Editor or NALC. Great care has been taken to ensure accuracy but NALC cannot accept responsibility for errors or omissions.

Deadline for issue No. 129: 1 May 2014

To make a donation please complete and return this form to: NALC Lower Ground Floor, 152 Buckingham Palace Road, London SW1W 9TR

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(A facility to do this will soon be available on the website)

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If you are a UK Tax payer, may NALC Gift Aid your donation? Yes No

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My Cancer Journey

As I look back, I realise I am quite fortunate to be writing this article. I followed the stereotypical pattern of a man's reaction to illness, having prided myself for years on not going to a doctor. Though I became aware of a problem in the spring of 2000 it took until May 2001 before I had myself checked out at hospital, after an immediate referral from my GP, when I finally did do something. I had experienced a persistent but mildly sore throat, followed by hoarseness, which led me to a brief internet search. This advised the likely cause – cancer of the larynx – so I knew what was coming.

By profession, I was a secondary school teacher. After successfully completing a degree course at Sheffield University I started my career teaching Physics to Oxbridge entrance exam level at a school in Chesterfield. Later I specialised in what was then called Pastoral Education. This basically meant dealing with the most challenging students in terms of behaviour and attitude. At the time my symptoms appeared I was an Assistant Headteacher with responsibility for 300+ senior students in an 11-16 secondary school. I loved the job; no two days were the same.

The diagnosis of cancer meant time off work for radiotherapy, then a brief return before a recurrence led to a laryngectomy. I had the offer of a partial removal of my larynx but chose, despite initial reservations, to have a complete removal to give me the best chance of being rid of the disease and getting a cure.

Computing Skills

I had a lengthy second spell off work and used this to develop my skills as a computer database developer. I produced databases for use within both my school and the local authority and I considered switching to working in this field permanently. I recall going into an appointment with my GP unsure as to what I was going to say to him. Was I fit to return to work or could I return to teaching or pursue a new career? In the end the words that came out were to say that I wanted to return to my job as a schoolteacher.

Before my operation I had done lots of research about valve speech. My enthusiasm for this solution led to me being the first patient to receive primary surgical voice restoration at my local hospital. However I found valve speech troublesome and problems with maintaining the seal on the baseplate were difficult to resolve, especially with trying to talk all day! Since then my primary method of speech has been to use an electrolarynx, with valve speech as a backup in the event of a discharged battery.

Back to Teaching

I had four years back in my job as a schoolteacher before taking early retirement. It made little difference that I was now speaking with an electrolarynx. I was useless in trying to calm down students on a noisy corridor but could do everything else. The students were fascinated on first hearing my new method of speech and negative reactions were very rare. I have met a few laryngectomees who have had great reservations about using an electrolarynx in public. I say go for it; 12 years' experience has convinced me that 99% of the people one meets are supportive and there is no cause for embarrassment.

At the time of my retirement my mother, over 90 years old, had to move into a care home. Initially my time was totally occupied

clearing and eventually selling the family home I had lived in until going to university in 1969. In the meantime my SLT had frequently mentioned the need for new members of the local laryngectomee group. Finally in 2008, now that I had time on my hands I went along to a meeting. Within a few months I was asked to become the Secretary of the group and I accepted the role, hoping I could make a contribution.



Though I had my laryngectomy six years earlier, I soon realised the benefit of sharing experiences of the day-to-day nuisances that neckbreathers have to contend with. Fellow patients can provide insights and advice that are beyond any clinician. My involvement grew and I accepted requests to visit patients about to face a laryngectomy and also decided to attend NALC meetings, representing my local group on the General Committee.

One of the best things about being involved with NALC is meeting so many great and inspiring people, who have contributed so much over many years. I cannot mention everyone by name but past-president Bert Culling and his wife Ethel have greatly influenced my work for NALC. I have travelled all around the country with Bert to attend events such as patient days or conferences and to publicise the work that NALC does on behalf of laryngectomees.

Ethel was a pioneer in the involvement of patients and carers in the area of head and neck cancer research. When she finally stood down as a member of the NCRI Clinical Studies Group, Ethel suggested I apply to replace her and I was appointed to the group in 2010. This work has involved me in reviewing proposals for clinical trials in the treatment of head and neck cancer. I have recently been invited to be a Co-Investigator on a new study about throat cancer.

I am almost as busy now as I was before I retired from teaching. The difference is that now I can, theoretically, say NO to requests to join or support various projects. In practice, saying no is usually quite difficult however!

I recharge my batteries by being a season ticket holder at Derby County Football Club. I make frequent trips to the Scottish Highlands and also enjoy exploring the music of J. S. Bach, a task I fear I will not complete in my lifetime!

I often reflect on what has happened to me. Prominent in my thoughts are the stupidity of ignoring warning signs for so long and the contribution I made to my own fate by having smoked from my late teenage years until my operation. My father died from lung cancer due to his smoking, but this had no effect on me, I carried on regardless. The changes in smoking habits of the population have finally led to a reduction in the number of laryngectomies that are needed, as has the development of alternative chemo-radiotherapy treatments. However, whilst ever there are patients that have to lose their voice box, I want NALC to be there to support them.

Malcolm Babb

A Letter from India

I was a Laryngeal Cancer patient about 22 years back in India. After surgery to remove my vocal chords, I lost my voice completely and suffered mental trauma and torture. I had lost something so dear that it was unbearable at that time for me. I was totally disheartened and demoralised especially as I thought of myself as disabled. My Surgeon, an angel, Dr Ashak Mehta, assured me that I would develop some vocal media by way of my oesophagus (windpipe). I slowly regained my confidence and, by adopting tremendous will power and hard practice for 10-12 hours a day, I regained my voice. Finally, with training under the Asian Foundation for Laryngectomees Association (AFLA) in Tokyo, in 1999 my hoarse voice almost returned to normal.

I believe that cancer is not the cancellation of life. I have also proved that cancer is curable, if diagnosed and detected in time, followed with appropriate recommended treatment. I am now so happy and proud of my new voice. Since 1998, I have been associated with the Cancer Rehabilitation Clinic (CRC) at Prince Aly Khan Hospital, Mazagaon, Mumbai., where I started my Laryngectomy Rehab.

Laryngectomee patients need emotional and moral support to restore them to normal life and are eager to meet survivors who lead normal lives. On this basis, Dr Sultan Pradhan, Oncologist and Head of Prince Ali Khan Hospital, created the Cancer Rehabilitation Clinic. Mrs Anaita Vesuwalla was a Founder-Member of the Clinic. I joined them in 1998 with a view to share my experience with patients. I received advanced Instructor training in

What Does NALC Do?

Do you know just how many activities NALC is involved in? Malcolm Babb has produced the following list showing how busy NALC is. Find out even more at the NALC website at: www.laryngectomy.org.uk/what-we-do

CLAN Our quarterly newsletter keeps members up to date with laryngectomee developments and activities in our affiliated clubs.

Education Programme We contribute sessions to training days for nurses and emergency service workers to advise on the needs of neckbreathers. We are a partner of the National Tracheostomy Safety Project.

Hospital Visits We can arrange a visitor for a patient before or after their laryngectomy.

Information for Clinicians We provide leaflets for medical staff especially nurses in hospitals, community nurses, emergency service workers and speech therapists.

Information for Patients We provide leaflet and DVDs to help patients before and after their laryngectomy operation. We are approved by the Information Standard as a reliable information provider.

Patient Days Information events for laryngectomees and carers are organised several times a year in varying parts of the country most

recently in Scotland and the East Midlands.

Providing a Patient Voice Our members provide a patient voice on groups organised by NICE, NCRI, NCIN and NHS England.

Research We support relevant studies and clinical trials in their applications for funding and our members contribute by reviewing patient leaflets and joining steering committees.

Social Media We have a Youtube channel and a Facebook page.

Swimming We can provide training and assistance to laryngectomees wishing to return to swimming.

Support for Local Groups Our officers visit clubs on request, especially to help new or changing groups.

Telephone Advice Our London office provides a nationwide resource for laryngectomees who need help and advice.

Website Our site provides speedy access to our information with material available for download and also all the news of planned events.

oesophageal speech in Tokyo in 1999. Our main activities are to give moral support to patients and their families. We try to give them an idea of what they have regained because of the operation. We explain the treatment, radiation, chemotherapy and surgery.

We suggest a proper diet, clothing and how to lead a normal life.

Patients come to the Clinic from all over India as well as Nepal, Bangladesh, Pakistan and as far as Saudi Arabia.

The photo shows laryngectomee patients at the Prince Aly Khan Hospital.

Pradip Lahiri

Shine Cancer Support



NALC is receiving more enquiries from those who are under 50 having a laryngectomy operation. We are able to give support and provide literature, but sometimes find it difficult to put people in touch with someone their own age.

Shine Cancer Support is the only registered charity in the UK exclusively focused on supporting people in their 20s, 30s and 40s with cancer. They support men and women, with any type of cancer.

Their vision is that every adult in the UK diagnosed with cancer in their 20s, 30s or 40s can access the help and support that they need in a way that suits their lifestyle, and that they are a part of a confident, supportive and empowered community of young adults living with cancer.

For more details

**www.shinecancersupport.co.uk or
email info@shinecancersupport.co.uk**



Larry on an Ambo!

After my laryngectomy operation, which included a radical laryngectomy, my job as an Ambulance Technician was in serious doubt – I work as a crew member on a double manned vehicle for West Midlands Ambulance Service. So, apart from the mental and physical trauma of what just happened to me, I had problems of saving my job (which I admit, I enjoy!). For the majority of you good people who will read this I have no need to go on about these ‘problems’ as you have also faced them yourselves, so enough about that!

So... here you go – before the operation I had various meetings with my station officer and HR about my future and it has to be said at the time all looked bleak – many questions arose:

- Could I continue in my role?
- Infection risk?
- Communication?
- My functionality in a front line emergency ambulance?
- The effect on me, emotionally and physically?
- Etc. Etc...

There was no template for a situation we were in for the service to study because, as far as all we are aware, there was no other service who had anyone return with a laryngectomy (please forgive me if I am wrong) in the UK. Basically it was down to me to take the lead and work out what to do. Choices were fronted: 1) removal from front line duty and to a less demanding role or 2) retirement due to ill health or retirement and a return part time employment within the service.

My Goal

None of these appealed to me, so I made the choice that I **would** return to my old job, I **would** find a way, I **would** get fit to do it and I **would** get my voicing to a level good enough. This became my goal, tunnel vision set in – I had taken a beating physically and mentally and I **would not** back off now!

Despite the rigours of the job, I returned with the full support of my station officer (who must get a mention) Paul Baylis, Helen from HR and the Union, but most of all – my family and friends in the service where in amongst them as some I also consider ‘family’.

Finally it was agreed that even though I was back as ‘crew’, I should take a more

non-clinical role so I took a demotion from a Technician to an ECA (Emergency Care Assistant). Unfortunately this involved me having to take a pay cut, quite a substantial one, much to the dismay of all involved (except the accountants and upper management!), despite protests, they had airtight reasons for this action, so I had to accept. But now this move removed responsibility clinically from my shoulders (the main worry was communication) though my voicing was excellent with both touch and hand-free cassettes, when outside i.e. motorway or in loud noisy environments I could not get above a certain volume, got round this by a bleep alarm (a loud one). So my rota place was among my friends, who are wonderful so all looked good.

Lump No 2

Then... lump number two surfaced. More sick leave, another operation plus radio therapy this time but back to work approx 4-5 months later.

Choices now had to be made, do I return as a Technician, run the risk of problems with the ‘communication’ side? The risk of litigation is always a shadow over the medical shoulder, would the service support me? Would I be leaving myself open to problems? Or do I bite the bullet and stay as I am? I bit the bullet, done and dusted.

So, life goes on, still working with my mates, doing the best we can. As time wears on, overcoming problems as they occur, I use Provox stabilisers along with the glue, I do shape and cut them to suit my neck and stoma, make them smaller, less obvious, it also works well with the Provox cassette and hands free. The weather is a big factor, hate misty damp rainy days – love sunny warm or hot days, this suits me a lot better, live in the wrong country really don’t I? I have to get up earlier to prepare for the day, but it is a price I am willing to pay to keep working.

Some patients are sympathetic, some fascinated, curious, some cannot take in the fact that I still do this job! Some are so wrapped up in their problems that they do not notice, till I speak! It is humorous to see people’s faces when they have called 999 for a trivial complaint, then I walk in. Some say my voice is sexy (women I hasten to add!). So being a Larry has only had limited effect on my working life, as said before, the weather is the biggest

bug bear! Our people in our control now know my voice and always give me time to ‘sort’ myself out if I need too! So onwards and upwards.

May I take this opportunity to wish you all the very best with your lives, I myself in a way have been ‘lucky’ as I am fully aware that there are a lot of you a lot worse than me, so I wish you all well and may whatever God you believe in, take care of you.

Nigel Goodman [catster57@yahoo.com]

He Must Pay

A husband and wife had a tiff. The wife called up her mum and said, “He fought with me again, I am coming to live with you.” Her mum said, “No darling, he must pay for his mistake. I am coming to live with you.”

Stilltalking, NSW Newsletter

Rarely Mentioned

Constipation is a subject rarely spoken of by Laryngectomees, but it is a problem suffered by many, not realising that having no vocal cords does have a great deal to do with it. An absolute essential part of going to the toilet is straining, and to do this a person will close their vocal cords, causing the pressure first in the chest, and a similar thing happens when lifting something heavy. But in Laryngectomees by not having vocal cords, we are unable to properly exert pressure in the body, to start the downward movement of the stool. We are always aware of breathing through this tiny hole in the neck, and always, are we getting enough air into the lungs? So many don’t exert the pressure that they could, and the toilet is not completed, with sometimes disastrous results, with stools hardened and impacted.

I personally exert pressure myself by cupping each hand, linking them and pulling hard against each other. My colorectal surgeon, is aware of this problem, and I take a Movicol Sachet daily to keep things moving, and a Fybrogel sachet daily to bulk things up. It is important to drink plenty of water when on these drugs.

Len Hynds, Speechless Poet

NALC Educational Programme



Alex McGuiggan



Bert Culling



Ivor Smith

The background to our educational programme stems from many concerns about treatment and care in non-ENT wards reported to our head office. We decided to look into this and as a result asked for the help of the National Patient Safety Agency (NPSA) who carried out a survey in 2004. In March 2005, after analysing the survey results, the NPSA issued a warning alert to all NHS trusts to ensure that health professionals likely to be involved in the treatment and care of laryngectomees would receive the necessary training to deliver such treatment and care.

We developed a verbal presentation but decided that an electronic version of this would be more beneficial. So we in fact developed a three module electronic version, under the guidance of Macmillan personnel, to be eventually delivered by laryngectomee volunteers. The presentations took over a year and a half to produce and were reviewed by a number of independent reviewers chosen by Macmillan. When Macmillan were satisfied that the presentations were fit for purpose and followed the correct format for educational presentations, NALC was given to go ahead to go live with them.

A number of us have been trained in the delivery of these presentations to a myriad of health professionals across the UK as part of staff development events held in Universities, Training centres, ambulance headquarters in NE England and N. Ireland, St John's ambulance centres and now more recently in some care homes as well. These professionals have ranged from paramedics to junior doctors, from ambulance paramedics to nurses, from radiographers to speech and language therapists and also first responders, especially in rural areas, many of whom have said that their training never included treating laryngectomees, and so they are grateful they now have this life-saving information.

Our presentations have and continue to be well received in all of these events and as a result the potential to ensure that laryngectomees get the correct treatment and care is greatly enhanced. Health professionals also as a result of experiencing the presentations have told us that they now feel more confident, competent and comfortable treating and caring for laryngectomees.

Increasing Demand

The number of engagements that we are getting is increasing year on year. This is to be welcomed as there is still a lot of work to be done to reach even more health professionals if laryngectomees are to feel safe accessing treatment and care anywhere in the UK. If you could help set up appointments for us to present in your area we would be pleased to service these requests. Please contact the office on either 020 7730 8585 or by email on info@laryngectomy.org.uk if you have any opportunities for us to take up.

The presentations have been modified to enable us to collect immediate electronic feedback from delegates at strategic points in the delivery of the presentations. This is invaluable to us as it enables us to have our own in depth evaluations. For the June edition of *CLAN* we will be able to collate all the feedback from the three trainers who are listed at the beginning of this article to let you have a report that contains both quantitative and qualitative analysis of education programme delivery opportunities and its impact.

Alex McGuiggan

Well Served

Members of the Plymouth Laryngectomy Club (PLC) read the article you had published in the December 2013 edition of *CLAN*, about the Valve Services Survey, very interesting. The consensus of our Club Members is that Laryngectomees in the catchment area of Derriford Hospital in the Plymouth area of Devon and Cornwall are served remarkably well both during working hours and outside of those hours and we all feel very privileged. All Laryngectomees are provided with Information Sheets explaining what to do and who to contact in an emergency. I can personally vouch for this as I had need for treatment on Boxing Day. I was seen by a doctor within a couple of hours of telephoning the hospital for advice (and was then admitted). You may also wish to know that we wrote a Letter of Commendation in November 2013 for one of our Speech and Language Therapists.

Geoffrey N. Read, MCIM

The Unexpected Choir

In an event created by JWT Brazil for the A.C. Camargo Cancer Center, the Unexpected Choir made up of Laryngectomy patients gave a performance to raise awareness about larynx cancer and its main risk factor: smoking. Twelve patients surprised the audience of MASP's auditorium, who were waiting for the USP (São Paulo University) Choir. They interpreted parts of The Beatles songs All You Need is Love and She Loves You accompanied by audiologists from the institution. At the end, they held up banners that read "Listen to this choir's voice: Don't smoke." The patients, most of whom are over 60-years-old, used oesophageal voice, prosthesis and electronic larynx to sing and catch the audience by surprise. You can check out their performance at:

www.psfk.com/2013/12/anti-smoking-choir-jwt.html#!qbGy0



Obituary

Rev. Clifford Hughes (1936 – 2013)

Jan Stewart, Treasurer of the Chinwags Laryngectomy Club in Kirkcaldy, Fife has told us of the death of a CLAN stalwart, Rev. Clifford Hughes. His obituary appeared in *The Scotsman* on 9 January 2014 and the Thanksgiving Service for his life was held in St Mary's Church, Haddington on 18th January. The turnout was amazing at the church where Clifford used to preach. A collection was taken for music at the church and for NALC. One of the most poignant moments during the service was listening to a recording of Clifford's singing (pre-op).

Jan says that Clifford was an inspiration to all who knew him. She had her op over ten years ago and could not speak for ten months. At the first meeting she attended, he immediately came over to her and introduced himself and gave her so much hope that one day she would be able to speak like him. She travelled down to London with him on two occasions to attend the NALC AGM. Once by plane and once by train. They had such fun, she doesn't think they stopped talking all the way!

Here are extracts from his obituary in *The Scotsman*.

Brutally Frank

When Clifford Hughes lost his voice to cancer, his reaction was brutally frank: "Can't speak, can't communicate – might as well be dead!" For a man whose career encompassed three voice-based professions – singing, teaching and preaching – it was devastating and drove him to the depths of despair. But, once he had run the gamut of bereavement responses, he bounced back with his own brand of self-deprecating humour, a trait that illustrated the joy he reaped throughout his life, no matter what he confronted. He summed this up in the following limerick:

A tenor called Hairy McKnees
Used to soar to top Cs with great ease
But his laryngeal op
Caused his voice range to drop
To basso profundo low Ds.

When later diagnosed with prostate cancer, his attitude was: "B***** it, cancer at both ends!" He laughed it off and got on with the business of living and raising awareness of the disease. (His) was a life that had taken him from boy soprano from South Wales to the world-renowned choir of King's College, Cambridge then on to become a tenor on the recital and opera circuit which he combined for a while with teaching in Scotland (at Hurst Grange Boys' School in Stirling in 1959 and, finally, to the ministry at St Mary's Parish Church, Haddington – a role he relished.

Fundraiser

In 1971, at the European Congress on Evangelism, he shared a platform with Billy Graham and Cliff Richard. In the mid-1970s, he took on the job of creating Beaconsgrange School at Bridge of Allan. After that he moved to Loretto School, Musselburgh as Headmaster of the junior school. But, by the mid-1980s, following the deaths of his father, mother and a sister from cancer, he became a fundraiser for Macmillan



Clifford Hughes with his daughter Clare, photograph Wattie Cheung

Cancer Relief, helping to raise £1 million for the Oncology unit at Edinburgh's Western General Hospital where he would later become a patient. He also created a musical meditation programme of scriptural readings which he presented at churches all over Scotland until friends suggested he might consider the Ministry... In 1993, he was ordained and inducted to St Mary's, Haddington.

Then, (in 2001) a surgeon in his congregation raised concerns about Clifford's voice which had degenerated into a coarse whisper. The diagnosis was cancer and his voice box was removed. "I thought my useful life was over," he said. He retired early from the ministry and learned to talk again. ...From being terrified that his speech would resemble a 'phantom burp', he was heartened to find he still sounded like himself, albeit at a lower timbre and was delighted when a woman in his congregation described his voice as "rather sexy".

Talk for Scotland

A leading contributor to the Scottish Government's first ever civic participation project for people with communication support needs, he helped to develop and promote the Talk for Scotland toolkit and Principles of Inclusive Communication to hundreds of policy makers and public sector staff throughout the country.

Having been diagnosed with prostate cancer after successfully reclaiming his voice, he faced the disease for a third time when pancreatic cancer was diagnosed last autumn. "It does not worry me," he joked. "I know I'm going to be well cared for." He died suddenly at his home in Kinross on Christmas Day and is survived by his wife Kathleen, children Rick and Clare and grandchildren Calum and Iona.

News from the Clubs

SPEAKEASY Club, Cornwall

Six club members attended the Alternative Laryngectomy Information Day held at Derriford, and all were very impressed with the organisation. There was a good attendance, with members from Cornwall, Plymouth and further afield. For lunch there was an interesting selection of soft foods prepared by Anton, a winner of Master Chef. After an introduction from Julia, formerly from Treliske, a photograph was taken for the *Plymouth Herald*. Dr Roy and Mr Malik gave a talk and answered questions on new developments in treatment; it was a surprise, and good to hear, that only six laryngectomy operations were carried out last year. A speaker from Macmillan gave information on benefits.

Ron Holman, who has travelled the world without problems, talked about travel and holidays; he recommended taking plenty of bottled water, having a valve change ahead of time, and an HME cassette to safeguard against infection and to moisten dry air, especially when flying. To make us smile he said the consultant's advice on what to do when drowning was "hold him upside down and let the water drain out"! He gave a very comprehensive list of companies who do travel insurance, and this is available on request. Trevor gave a presentation on an ultrasonic nebulizer which can be used from a car battery – useful for travelling.

On 11 December 2012 they had their joint Christmas lunch (with the Recovery Club) at Truro Cathedral restaurant. In 2013 they held the following events: A very interesting and well presented visit to Cornwall Air Ambulance in April. Annual General Meeting in May. In June, they joined the Recovery Club for lunch and a raffle at the Queens Arms in Botallack, followed by a walk to the atmospheric remains of mine buildings on the cliff top. A delightful visit to the sixteenth century Melinsey Mill and lunch, in July. In September they were all invited to Valerie and Nigel's new home for what we were told was a ploughman's lunch, but turned out to be the most amazing spread of delicious food. Afternoon tea at Janet and Martin's home in November, with tempting home made cakes.

Their plans for 2014 include: 2 April: The Living Aircraft Museum, Classic Air Force at St Mawgan, which has been highly recommended. Wednesday 7 May: Annual General Meeting. Wednesday 4 June: Shipwreck & Heritage Centre at Charlestown – Europe's largest private collection of artefacts from over 150 shipwrecks plus collections from Cornish mining and china clay, and scenes from village life in days gone by.

Maidstone, Mid Kent & Medway Laryngectomee Club 'MMM'

The Club have never contacted CLAN before but they have told us that they have had a most entertaining summer this year. Their first outing was to RHS Wisley Garden Centre and their Language Therapist, Jenny Evans, very bravely drove them there in a minivan. Then in May they took themselves to Hall Place in Bexleyheath, had a wander round the lovely grounds and then had a very nice lunch in their charming new restaurant beside the River Cray. In August they visited the Brogdale Fruit Farm, Faversham for their Cider Festival and, despite the very heavy rain, the brave members who made it had a great time. We had our Christmas lunch at the Watts Charity on the 14 December and (as you can see from the photograph) it was just as good as last year!



Hippotomonstrosesquippedaliophobia: Fear of long words

The Windpipers, Blackpool

Their Christmas meal at the St Ives, St Annes-on-Sea was a good night and the resident compere as always did a brilliant act with his stand-up Bingo, novelty balloon making and various other games. They all stayed overnight and had a delicious breakfast next morning. Their January meeting was at The Guards' Club, Whitegate Drive, Blackpool.

Laryngectomee Swimming Training Restarts



For over two years NALC's swimming trainers have been unable to help laryngectomees to return to swimming. The problem arose because swimming pools needed the sessions to be covered by an indemnity insurance policy. A search for cover from a Lloyds' broker led to a quotation of several thousand pounds annually, which was not affordable. Finally we have managed to secure cover for a significantly lower amount and swimming activities can be resumed. Additionally we will, on request, try to extend the cover to other laryngectomee swimming groups around the country who need insurance. However we may have to seek a contribution from such groups towards the additional costs involved, given NALC's new financial circumstances.

Your Retirement

The idle life, that you will lead,
will be like a pleasant sleep
wherein you rest and heed
those dreams that passed you sweep.

And still of all your dreams,
that in turn so swiftly pass,
each in its fancy seems
more noble than the last.

And, each evening, you will say
noting this life of bliss,
that you have never known a day
in all your life like this.

Len A. Hynds

News from the Clubs

How You Can Help NALC

By Joining Us

Do you have some experience and skills in fundraising? We will be setting up a committee to develop activities to raise funds to replace the cuts in our grant from Macmillan, phased over the next two years. We would welcome the involvement of members of our wider community who could add their expertise. As is usual for our committee members, travel expenses will be paid for attendance at meetings.

Please contact Vivien Reed at the NALC office if you are interested and willing to help us in this way. Contact details are on the front of this newsletter.

By Donating

Please consider supporting NALC in one of the following ways:

USE THE FORM ON PAGE 1 to

Send a donation to our office

Set up a standing order for a monthly payment

Make a donation via a card payment.

By Visiting the Website

Shortly there will be a facility on our website to make a donation using a debit card or credit card. Please also submit the details that allow us to claim Gift Aid.

By Organising a Fundraising Event

Could you or your club organise a coffee morning or similar event? We can advertise such events on the website and in *CLAN*, to help maximise your success!

By Sponsoring Events

Could you or a friend or family member take part in a local or national sponsored activity to benefit NALC? We will help by appealing on our website and elsewhere for sponsors to support you. Again, that would help with your efforts.

Whichever way you could help us, it would be most appreciated, and of enormous benefit in helping us to continue – and expand – the vital work we do at NALC in helping to support the laryngectomee community, and improve services, across the UK. We look forward to hearing from you. *Malcolm Babb, NALC President*

The Broken String

As many of you may know, Itzhak Perlman is a famous violinist who contracted polio as a young boy. As a result, he walks with great difficulty and with the aid of crutches. One day, Perlman was scheduled to give a recital at Carnegie Hall.



As usual, he came onto the stage with crutches, laboriously walking to his seat. A few bars into the concerto, one of his violin strings broke with a loud popping sound. The conductor stopped the orchestra, and the audience held its collective breath as it waited to see what would happen next. Would someone appear from backstage with a new violin? Would Perlman pull a new violin string out of his pocket? Instead, after a short pause, he nodded to the conductor to resume where he had left off. The common wisdom is that it is not possible to play a violin with three strings. That evening, Perlman refused to know this. He played the entire concerto on three strings. When the concerto ended, the audience rose with thunderous applause, clapping and stomping and shouting. When the audience finally quietened down, he said: "It is the artist's task to find out how much music you can make with the instrument that you have."

Survivorship

Survivorship is about living life fully with changed instruments: changed bodies, changed psyches, and changed perceptions. We all emerge from our treatment different than we were. Many of us are not as resilient. We may be changed physically or have an altered perception of our vulnerability and sense of mortality. The challenge is to figure out how to live as loudly, fully, and richly as we can, post diagnosis.

*Reprinted from Second Wind Newsletter
Submitted to Webwhispers Mail List Jan
2014 by Hank Luniewski*

Plymouth Laryngectomee Club

Ten intrepid Club Members met up at the China Fleet Club at 12 noon on Tuesday, 10 December 2013 for the Annual PLC Christmas Luncheon. It was open to all Members and Friends of the PLC and official guests. They had a Phantom Santa. As in previous years, Members brought along a wrapped gift not exceeding £5 in value and marked it MALE or FEMALE or NEUTRAL. On Tuesday, 14 January 2014, they held their monthly meeting at the Mustard Tree Cancer Support Centre. In February they planned to have Stafka Scragg give a talk on Laughter & Relaxation. Then on Tuesday, 11 February 2014: they had an outing to The Vue Cinema, Plymouth.

Their *Newsletter* recently reported on the two 'little soldiers' suffering from Tracheo-Oesophageal Fistula (TOF) which only

affects around one in 3,500 children. There was also an article in the *Plymouth Herald* about it. Well, the club made a cash donation of £50 to TOF and their photograph shows six-year-old Kyle Thorne and two-year-old Spencer Mclelland with family and friends on their Burrator ride. The two little charity fundraisers battled wind and rain to complete a charity challenge.



Happy Larrys, Liverpool

Here is a brief rundown of their year: In 2013 they have had frequent lunches at the Adelphi Hotel in Liverpool and the Prince of Wales Hotel in Southport. They also had a coach trip to the Lake District and enjoyed several outings to the theatre. Some of them (pictured below) rounded off the year with a Twixmas break at the Hydro Hotel in Llandudno which was thoroughly enjoyed by all.

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