

# CLAN

THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS NEWSLETTER

Issue No. 127

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### President's Christmas Message



I had never really expected to be writing the President's Christmas message and this is my first following my appointment as President last May. I would like to pay thanks to my fellow officers of NALC, past and present, for the encouragement and support I have received. Like my predecessors I have benefited from the hard work done by Vivien and Kerry in the NALC office.

I am sure I am not alone amongst the laryngectomee community in not really enjoying the winter season. It seems to magnify some of the nuisances that we put up with and being outdoors in really cold weather can be very uncomfortable. One of the reasons I look forward to Christmas and the New Year is that it immediately follows the turning of the tide. The days then are getting longer and we can look forward with a bit of optimism to the spring.

I send Christmas greetings to all laryngectomees, their carers and families and wish you good health and happiness in 2014. Seasons greetings to the many clinicians and also to friends from outside the United Kingdom who read and enjoy CLAN.



Malcolm Babb  
President



## A WORD FROM THE EDITOR

### BUSY AND EXPENSIVE!



Can it really be Christmas-time again? Time seems to go so fast since retirement a couple of years ago! It's been a very busy year in the Editor's household. Trips to the Holy Land and Iceland – not to mention the Harz Mountains in Germany. And then the wedding of one of our daughters in September. So, not just busy but very expensive too!

Looking back for a moment, Ivor Smith has written suggesting we might reprint some articles from the past which newer readers may have missed. If you can think of any that would be particularly interesting or useful to 'younger readers', please let us know. We include in this issue a cartoon from the past by Andrew Staines who regularly provided cartoons for many years. Andrew is very much still around and occasionally visits us when his health allows. He's even said that if you provide new ideas for cartoons, he'll do the drawings!

### Life Beyond Cancer

Well, it's another packed issue for Christmas reading. Of special interest is news that Rev. Clifford Hughes's daughter, Clare, is working on a dance production based on his experiences of 'Life beyond Cancer'. If we manage to get photos, we'll print them in a future issue. Meanwhile, have a very Happy Christmas and New Year!

*Ian Honeysett*  
Ian Honeysett (Editor)

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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. 128: 1 February 2014**



# The Movie Stars

When I was asked earlier this year by Janice Lang, my speech therapist, to appear in a film being made on behalf of the Christie Hospital, Manchester, I was only too pleased to oblige. I had received radiotherapy treatment there five years earlier and had been impressed by the courtesy and care I had received. So if I could repay them in any way, I was up for it.

A diagnosis of cancer on one of my vocal chords had necessitated the surgical removal of my voice box. This had been carried out in September 2007, not at the Christie but at Fairfield Hospital in Bury. All the staff there including the surgeon had been very kind to me but, one cold morning in early December when he rang my husband at home, my outlook suddenly became decidedly chillier. He told him that I had been discussed at the regular meeting of consultants and my oncologist had said that he considered a month-long course of radiotherapy to the surrounding tissue would be advisable. Offered the choice between being in hospital for a month or attending daily, I opted for the latter.



So, two days into the New Year and not really understanding what was about to happen to me, we commenced our early morning 20-mile trek down to the Christie. Fortunately, after recovering from the effects of the radiotherapy and regular check-ups, both at Fairfield and North Manchester Hospitals, I was finally told in October 2012 that my presence would no longer be required. Hooray.

## Off Like a Shot

"Could you attend with your friend Philomena (who is also a laryngectomee) at the Bali Health Spa in central Manchester where the filming would take place?" We were off like a shot.

It was bitterly cold day that day too in late March, but the warmth of the reception we received more than made up for it. The film crew were unloading their equipment when we arrived and the narrowness of the street had ensured the inevitable honking of horns. So, when my husband completely blocked the street to drop us off, it was like a fanfare for the famous.

Once inside, we were greeted by Ben, representing the Christie, and Damien from the film production company. Both were charming young men who introduced us to Karen, a fellow laryngectomee who would also appear in

the film with us. Her bubbly personality combined with Philomena's leprechaun wit was just right to lighten the proceedings. Three young lady therapists had been assigned to look after us whilst we were 'interviewed on camera' – Beyonce eat your heart out!

The white towelling robes didn't do much for our film star image but the head and neck massage that followed was very pleasant indeed. After that we tried to resist the tea and cakes but couldn't, telling ourselves they were a vital accompaniment to the gossip that we then indulged in.

Our contribution would form the last component of a three part film aimed at giving as many cancer patients as possible the reassurance that the disease can be survivable or 'lived with' whilst enjoying an acceptable quality of life. Terms such as 'survivorship', 'living with and beyond cancer' and 'mind and body' all, of course, tremendously and seriously important themes in the film, were being used, but by this time we were in full 'diva' mode and encouraged to tell it 'our way'.

## The Premiere

Then in mid-July it was time for the 'premiere'. The film would be shown after dinner, on the big screen at the Manchester Conference Centre and we were invited. So, in best frocks and with the excitement unbearable, we attended with some 40 or so others including Janice, our speech therapist. All had been involved to a larger or lesser extent in the making of the film. They included six other 'stars' who had appeared in parts one and two. They were all such interesting people

and included a sculptress and a professional musician. The stories of how they had coped with a variety of cancers were a humbling experience yet much of the evening, including during the showing of the film, was filled with laughter.

Alas, inevitably, much of my performance – and I expect that of the others – had fallen to the cutting room floor. No offers of a contract have yet been received. The following week, and in glorious weather, we attended what can be best described as a 'garden party' held in the conservatory and among the rose beds at the Christie. It was the launch of the new website ([www.christie.nhs.uk/the-foundation-trust/patient-information/living-with-and-beyond-cancer/mind-and-body](http://www.christie.nhs.uk/the-foundation-trust/patient-information/living-with-and-beyond-cancer/mind-and-body)) and the introduction of the film to various professionals, volunteers and patients.

Dozens attended, and doesn't it make such a difference when the sun shines? Conversations and banter tripped lightly through the next three hours before it was all over and I returned home to get the washing in.

The film has been so professionally prepared, and the message it contains so reassuring, that I would recommend everyone to take a peep. It can be opened on the above website or viewed on Youtube.

We all long for clarity of understanding of our disease but this usually eludes us. The



consultants necessarily trim off the clinical complexities that would only confuse us, and instead try to leave us with a clear-cut idea of the treatment that will help, and even cure us. We then ponder on all that has been said and search for the answers, the ethics, and the morality that has allowed this 'thing' to invade our bodies. But the inevitable 'why me?' always remains unanswered. Although I was told I had the classic 'smoker's cancer', I had never smoked in my life. Although feeling clean of the guilt of having caused the cancer myself, it didn't help. The nasty complexities of real life don't allow for it. There was nothing I could do to cure myself. The question was how I could survive until the experts could get rid of it for me.



### Hard to be Positive

Developing a positive frame of mind did not come easy. My brain had gone to work and come up with nothing but negatives. The more ill I felt, the more desperate they were.

My own method was to try and feel happy about everything else in my life such as my home, my life-style, my three sons and their families, and, of course, my ever-supportive husband. I did not actually sit down and make a list of all the good things but I wish I had.

I hope that you will think our little film is a good thing too. I think you will.

*Hazel Barker  
The Oldham Quiet Ones Club*

**DATE FOR YOUR DIARY**  
**Wednesday 26 February 2014**  
**Laryngectomy Day**  
**Nottingham**

Further details will be on the website  
in the New Year and available  
from Head Office

## Family Matters

Hi, Patricia Morrison here with what I believe to be some very important information that I would like to share with fellow Larrys. I was diagnosed with laryngeal cancer back in 2007 at the age of 34. Just four years after my diagnosis my brother Gerard was also diagnosed with laryngeal cancer at the age of 39. This had a huge impact on us as a family but the main concern for us as a family was our other brother John who was an identical twin to Gerard.

Once Gerard had fought through and found himself clear and well on his way into remission, as a family we decided to pursue the concern we had for John with John's GP. Initially John was unheard and his GP refused to do any testing at all. Angered by this I decided to make a second appointment with his GP and accompanied John myself. During this appointment I found myself demanding that something should be done. After a lengthy discussion, the GP agreed to do a referral to a Consultant in Clinical Genetics.

A while later, John received an appointment with a Dr Ian Ellis, a consultant in Clinical Genetics. During the consultation, Dr Ellis spoke of a Professor McGrath in America who had just that day released an article in which he had found a genetic link in head and neck cancers. Dr Ellis asked permission to take some of my blood and keep it in storage for genetic testing and assured me and my brother John that he would do everything he could to make contact with Professor McGrath and that he would get back to us shortly.

### Good News

I am delighted to say that a few weeks later we got the news that Professor McGrath had agreed to take our case on and he was going to go ahead and test my blood for the gene ATR which has been linked to a family with head and neck cancer in America.

Also since the consultation I am very pleased to say that Mr Tandon, a consultant in the ENT department of Aintree Hospital Liverpool, has agreed to begin a screening programme for my brother John. A screening programme that will consist of regular six month checks and this will be in place for the next five years as it stands. More good news is that my brother John had his first screening today and got the all clear which is a huge relief for the family as a whole.

I believe this news is not only fantastic for us as a family but for laryngectomy patients as a whole and of course their families. This is a real positive step forward and I urge any other Larrys and their families with similar concern to use this information and to push forward for similar testing to be done for themselves.

As a family we wait with baited breath to see if the gene ATR has been identified through the genetic testing of my blood. As of yet we are still unaware but I can assure you as soon as I get any more information on this I will keep everyone informed via CLAN. I would also be very interested to hear of any other families that have had similar experiences. Also if anybody would like any advice or would like to speak about this then don't hesitate to contact me via my email at Pmorrow@hotmail.co.uk .

*Patricia Morrison*

## From the Archives

As you know, I have been a laryngectomee for a lot of years and was recently talking to a fairly new laryngectomee about some information that was in CLAN a number of years ago that he had never heard about. This got me thinking about how many good tips had been reported in CLAN over the years that new laryngectomees may not know about. I was thinking would it be a good idea to re-run some articles from a few years ago. This would both refresh older laryngectomees and give information to new people.

Unfortunately I don't have a lot of back copies to check. I do remember that we always had some cartoons; these could

also be re-run as they would still bring a smile to a lot of people including me. Possible some of the poems could be re-run; all this is still relevant today as it was then and the nature of our problem we are getting new readers all the time. This section could be called something like 'From the Archives' or some similar name.

*Ivor Smith, Vice President of NALC*

*(What do CLAN readers think? Do you recall any tips that were featured in CLAN which you found particularly useful? If so, the Editor is ready to trawl the archives and reprint them. In the meantime, we will include some of the cartoons we have published in the past when we were fortunate enough to have such talented cartoonists as Andrew Staines and Iain Jack. Editor.)*





## Goodbye, Stan

*The Rev. Colin Salter has sent us the text of his eulogy at Stanley Edgcumbe's funeral at St Michael's Church, Helston, Cornwall on 23 October 2013. Stanley was well known to many in NALC and so we are pleased to include this tribute to him.*

Stanley Edgcumbe had his voice box removed the day after Boxing Day 1981. With his wife Edie he lived through the challenges all laryngectomees face, without a voice or good communication, with breathing difficulties, and the danger of drowning in the bath or the shower. He learned to use oesophageal voice, a 'controlled burp', to communicate. These voice prosthesis as I wear were only brought into use around the turn of the century, too late for him.

Trying to help others, Stan was soon in leadership at the 40 Club, the 40th started local area club from the National Association of Laryngectomee Clubs. He saw its main benefit as 'meeting others to share life's experiences'. In 1991 he became a National Vice-President, helping sort out Government benefits, and their recognition of this disability being as challenging as any other amputation.

### 'Our Story'

I met Stan at his home in 2007, interviewing him three times for 'Our Story', the new Speak Easy Cornwall's book of patient and carer stories. His story is chapter one as he was our longest serving member. He proudly showed me an orange pair of disposable tweezers he used daily to clean his stoma. "26 years," he said with a twinkle in his eye. "Not bad



for a throw away pair, eh?" In 2010 we put on 'learning to swim as a laryngectomee' classes up at a hotel by Constantine Bay on the north Cornish coast. Stan drove himself up and was warmly welcomed by Bert Cummins from Sunderland who had come to teach. They had served together on the NALC Executive years earlier.

Stan knew me as a clergyman. He used to tell me of learning about God at the little Mission Church Sunday School along the road where he now lived once again. He was now in sheltered accommodation. When he was first in the street it was "two outside loos between four two bedroomed terraced houses"! His personal faith was shown in the hymns he chose for today's Thanksgiving service:

"O joy that seekest me through pain,  
I cannot close my heart to thee:  
I trace the rainbow through the rain,  
And feel the promise is not vain,  
That morn shall tearless be."

Stanley Edgcumbe, a Club member sadly missed, but fondly remembered for his kind and generous hard work.

## Valve Services Survey – Can You Help?

One of NALC's medical advisors, Professor Patrick Bradley, has recently had an article published detailing the results of a national survey he carried out with the assistance of colleagues from around the country. The survey asked Speech Therapists or Nurse Specialists about the services they provide to laryngectomees to maintain and replace speech valves and their opinions of the service. The findings are given below.



*Professor Patrick J Bradley (photo from EHNS website)*

There is considerable variation around the country. The clinicians who provide services at hospitals, which are, specialised surgery centres, are happier with the service they are able to give than those at other centres. Many trusts do not have a written care pathway for dealing with emergency laryngectomee situations. Out of hours it is A&E rather than ENT wards that now increasingly handles the provision. It is felt there is a need for more training for out of hours staff on issues such as leaking valves, mucus plugs and aspiration.

So how are things for you? NALC would like to hear your views of the service you get, whether it is excellent or perhaps needing some improvement. The process of centralising services is continuing and we are keen to find out if this is causing extra problems for laryngectomees.

You could contact us by email to [info@laryngectomy.org.uk](mailto:info@laryngectomy.org.uk) or visit the website [www.laryngectomy.org.uk](http://www.laryngectomy.org.uk) and click on the 'contact us' button; by phone to NALC on 020 7730 8585; or by writing to NALC at: Lower Ground Floor, 152 Buckingham Palace Road, London SW1W 9TR.

Thanks for your help.

*Malcolm Babb*

## Chocolate Peppermint Mousse

### Ingredients

2 large bars of white chocolate, broken into pieces  
1 pint double cream  
Few drops of peppermint essence  
Mint leaves to garnish

### Method

Whisk the cream until it thickens and forms soft peaks. Melt the chocolate in a bowl over a saucepan of boiling water. Once the chocolate has melted, remove the bowl from the heat. Fold the melted chocolate into the cream then add the peppermint essence. Pour the mixture into one large or several small bowls/ramekins. Place in the fridge and leave to set for two to three hours. Garnish with mint leaves.



*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.*



## Keep Smiling!

I always enjoy Len Hynds' contribution to CLAN but was saddened by his two verse poem The Pretence. He is so right to refer to the Bereavement Responses we inevitably pass through when a laryngectomy operation removes our spoken means of communication. Our voice is a fundamental part of our character and personality. I'd enjoyed three voice-centred careers as teacher, singer and preacher and can well remember reaching DESPAIR. "Can't communicate: might as well be dead." I'd experienced DISBELIEF: remember McEnroe's petulant outbursts at Wimbledon? "You cannot be serious!" ANGER: Jesus cried out "My God, my God, why?" quoting from Psalm 22. Haven't we all shaken our fists and echoed his words? But at length we come to ACCEPTANCE, or, even, in St Paul's words, "Rejoicing in my infirmity!" And laughter, surely, is part of that.

Laughter releases chemical endorphins, those feel good hormones, which make us feel better. Two years after laryngeal cancer (2001) I was diagnosed, with 'moderately aggressive' prostate cancer. A month or so ago my oncologist told me that a routine scan had revealed something nasty, about the size of a 50p piece, on my pancreas. Cancer number three: pancreatic cancer. So back to the creative therapeutic message of the limerick!

Keep smiling, whate'er comes to pass  
Too soon yet to push up the grass  
*(should be 'daisies' but that neither  
scans nor rhymes!)*  
No need to complain  
It's chemo again  
A kick up the old pancreas! 😊



Clifford Hughes with his daughter Clare, who is working on a Dance Production 'Life Beyond Cancer', based on Clifford's journey through cancer using four dancers, film, music, movement and Clifford's 'voice over'. The photographer was Wattie Cheung.

My smile, dear Len, is NOT a mask! It doesn't lie. It's part of my new positive persona, what one might call Life Beyond Cancer or, to quote Jesus again: "Life in all its abundant fullness!"

Rev. Clifford Hughes

## A 'Right Royal' Afternoon in York

**Where better to enjoy a splendid 3-course lunch, on a beautiful sunny day on 1 September, in an amazing historic City, and in the sumptuous surroundings of the Royal York Hotel...**

As we all greeted each other, and gathered in excited anticipation in the Hotel lobby, drinks in hand, and then in our Dining Room's reception area, we could just see the finishing touches to our tables being laid out by a small army of extremely busy Dining staff, who were checking diligently to see that everything was in order.

### A Good Turnout...

Then, given the word, around 70 of our NALC Club Members and some of their families, were gently ushered to their designated tables, all tastefully arranged around the grand Dining Hall, overlooking the 'best side' of the Hotel, and its beautifully kept gardens.

The atmosphere built slowly, as old friends renewed acquaintances, new friends were introduced, and colleagues shook hands – and Officers greeted the various Clubs scattered around. Club Members had come from all over the UK, including Amersham, Belfast, Calderdale, Carlisle, Chesterfield, Harrow, Lothian, York (whose Members didn't have far to come!) and London.



### A Delicious Meal...

After a brief 'Welcome' and introductions from our President, Malcolm Babb, and then from our Honorary Treasurer, Alex McGuiggan, and from Vivien Reed, our Association Secretary, we said Grace, and then tucked into our starters of either Leek & Potato Soup, or Chicken Liver Parfait, followed by a main course of either large slices of Roast Topside of Beef, with honey-glazed root vegetables (and Yorkshires, of course!) or delicious Baked Salmon, or Wild Mushroom Risotto.

By this time, the room was buzzing with lots of chattering, laughing, and smiling faces of Club Members, all tucking in and spasmodically finding the ability to talk and eat at the same time (as is our want) but – judging by the general noise levels and rising heat – everyone seemed to be enjoying themselves (and not to mention, for some of us, the drinks) very much.

### Room For Sweets – And Time For The Raffle...

The Sweets choices of either Strawberry Ice Cream Parfait or Baked Apple Delice Tart were whisked in as we finished our 'mains', and then, after a few pauses for breath, Vivien announced the sales of the Raffle Tickets, which were duly snapped up by all and sundry, ready for the Big Draw.

I would think by now these after-event Raffles are now a famous – and eagerly-awaited – event in any NALC Club's gathering. As in previous times, there were lots of interesting prizes, mainly donated by each of the attending Clubs, and many winners, too!

### Until Next Time...

As the proceedings slowly came to an end, we all said many fond goodbyes to Club colleagues, newly-found Members and associates, and then gently drifted out of the Dining Room and into the Hotel Reception – either heading home, or for a quick explore around York's many fascinating old streets and buildings, to walk off that delicious lunch, or for a quick nap somewhere!

All in all, another successful NALC Lunch event! I think most of us went home with many happy memories of the afternoon, a promise to keep up with new friends met there, and with a resolve to definitely attend next year's event – wherever it takes place!

Andy Gage





## Laryngectomy is Not a Tragedy

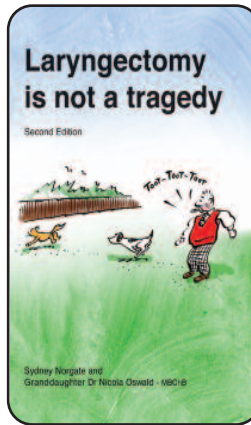
The Cancer Laryngectomy Trust has published a second edition of the late Sydney Norgate's book which has been updated by Dr Nicola Oswald, one of his granddaughters. She has written on current speech methods. They have kept all the chapters which Sydney wrote originally as they have been assured by health professionals that it is still highly relevant today.

The book is full of practical advice and information as well as reassurance. Sydney writes from personal experience of the problems caused by the loss of normal speech and describes the method of learning to use substitute 'pharyngeal' speech.

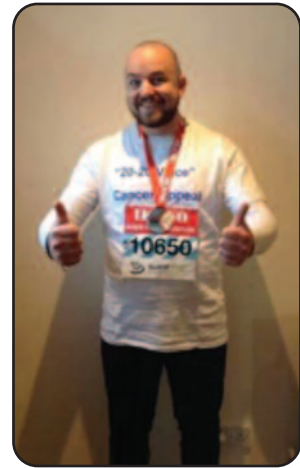
Here is a brief extract to give you the flavour of his style: "Among laryngectomees, I have encountered some disquiet about those who fail to regain speech of any sort in the absence of any physical explanation and I have wondered if the manner of approaching the problem could be the reason. I have found that, four days after surgery, simple words like 'cheers', 'twitchgrass' or the name of a loved one are well within the capabilities of patients. I believe quite firmly that no patient who speaks at that stage can possibly fail to learn at least one consonant speech even if full voice is beyond him. If the voice thus produced can be taped and played for the benefit of near relations, then the joyful ride to rehabilitation will have begun.

"On this adventurous journey there is no turning back. Is it possible that sometimes communication has been sacrificed at the altar of a god called Voice for so long that it is too late to recapture the possibility of speech of any kind? In putting this question, I aim to focus attention on the plight that my fellow laryngectomees may find themselves in and hope that my experience will give them hope. On a much more cheerful note, I was very amused recently to read that whales breathe in a manner very similar to laryngectomees and wondered if a corollary of this would be the assumption that we laryngectomees are having a whale of a time."

**The book costs £4.95 and is available from the Cancer Laryngectomy Trust at PO Box 618, Halifax, West Yorkshire HX3 8WX; telephone: 01422 205522; email: [info@cancerltf.org](mailto:info@cancerltf.org) ; their website is: [www.cancerltf.org](http://www.cancerltf.org)**



## A Merry Man



'20-20 Voice' had a runner in the Robin Hood marathon, over the full distance, on Sunday 29 September. A huge shout out to Ben Cunningham who ran the F U L L

distance in Nottinghamshire for 20-20 Voice Cancer Appeal. It was a roasting hot day and Ben completed the gruelling 26 miles in a heroic 5 hours 40 mins.

In completing the course Ben managed to raise around £350 for the '20-20 Voice' Cancer Appeal, which is now over half way toward its first target purchase to help head & neck cancer patients.

Congratulations on a marvellous effort, Ben.

## Belfast Laryngectomy Support and Information Day

The Belfast Laryngectomy Day was held jointly by Cancer Focus and NALC in the Malone Golf Club on the outskirts of Belfast on 25 September 2013.

In total over 40 laryngectomees including their carers attended this event. The venue was superb and very picturesque.

We had valuable inputs, including:

- A talk from an ENT surgeon on issues affecting laryngectomees
- CNS nurses gave a revealing talk on refreshing, and how to use the suction pump
- Patient Client Council talked on how they represent and campaign on patient concerns, plus -
- Citizen's Advice Bureau on welfare reforms, and -
- Laryngectomy supplies representatives presented the latest devices and equipment.

The event ended with a lovely hot lunch at the golf club. Everyone in attendance was very complimentary of the content of the event and was looking forward to the next one.

Andy Gage

## Dr Blom in Australia

On 24-25 August 2013, the 'Dr Blom in Australia' course, run by Julia Maclean at St George Hospital, was a great success. The course is aimed at speech pathologists new to TEP and voice prosthesis management. It provides one day of theory based learning and then a second practical day, where voice prosthesis can be changed and re-sized under supervision. This is the 11th year that the course has run with over 300



participants over the years. The highlight of the course is meeting the volunteer laryngectomy patients and hearing their individual treatment stories. (Along with a great deal of humour that the volunteer patients bring to the course.) Speech pathologists from NSW, Victoria and Perth attended the course and left with good voice prosthesis problem solving skills and a good network of fellow speech pathologists caring for laryngectomy patients.

(from Still Talking, NSW newsletter)



# News from the Clubs

## Speak Easy, Cornwall

Their newsletter details an Alternative Laryngectomy Information Day by the Speech and Language Therapists of Cornwall, Plymouth, Torbay and Exeter at the Mustard Tree Cancer Support Unit at Derriford Hospital on Friday 25 October. It was free to attend and lunch was also free! On 2 October there was a meeting at the Victoria, Threemilestone to discuss a revised version of the Speak Easy introduction colour leaflet, which is now rather out of date. 11 December is Christmas lunch at Truro Cathedral restaurant. The Recovery Club will also be there to join in with their annual lunch.

## Chinwags Lary Club, Kirkaldy, Fife

It is with great sadness that the club has announced the death of its Chairman, George Stewart, on 29 July 2013. George and his wife, Nancy, worked tirelessly organising and fundraising for the club. Every year he grew plants in his greenhouse and then sold them on for contributions to club funds. He was always the first to welcome new members and make them feel at ease. The club will sorely miss his presence and they are so grateful for all that he and Nancy contributed to the Chinwags Club (which meets every second month at the Maggies Centre in Kirkaldy).



## Plymouth

The Club has produced a flyer for 2014 which also includes an invitation to laryngectomees to join them. It has a very inviting photograph too! Club meetings are on the second Tuesday of the month and alternate between The Mustard Tree and Awaydays.



Their newsletter includes this item: **Plymouth Cancer Care Good... but More Nurses Needed.** This article was published in the *Plymouth Herald* by Sophie Taylor on Saturday, 31 August 2013: Hundreds of cancer patients surveyed at Derriford Hospital at the end of last year felt there were not enough nurses on duty most of the time, it has been revealed. But the independent survey, commissioned by Quality Health, also revealed that the majority of adults who had been admitted to Derriford Hospital as an inpatient or as a day case cancer patient between September and November 2012 felt the care they received was excellent or very good. The survey found that only 50% of those who responded to the survey felt there were always or nearly always enough nurses on duty... a decrease of 11% based on last year's results. However, the Trust scored in the top 20% nationally in areas such as patients given choice of different types of treatment; information about support groups; explanation about surgery; and controlling radiotherapy side effects. It also had year-on-year improvements in 12 areas including communication, provision of verbal and written information, patients' views being taken into account, privacy, patients not feeling as though they were treated as a set of cancer symptoms, and patients' views being taken into account by doctors and nurses when discussing their conditions and treatment.

## The Windpipers, Blackpool

In July, the lady Carers from the group had a Spa day and lunch at Ribby Hall, Wrea Green, Preston which consisted of an 'Aqua Thermal Journey' (saunas, steam rooms, Jacuzzi and a hot tub outside). It was 'totally invigorating' and one of the lady laryngectomees also had a pedicure. She said afterwards that she was 'walking on air'. Everyone enjoyed the day and they can't wait till they go again! They had planned for the men Carers and laryngectomees to do Archery but, due to a delayed lunch, they were unable to do so.



Photo from 'The Railway Children' much of which was filmed on the Keighley & Worth Valley Railway. Taken from the railway website: [www.kwvr.co.uk/family-fun.html](http://www.kwvr.co.uk/family-fun.html)

Then on 27 July, there was a Club visit to Skipton and Keighley and the Worth Valley Railway to Haworth, home of the Bronte sisters. While in Skipton, the Saturday Market was on and, for lunch, they visited the famous fish and chip restaurant, Bizzie Lizzies. As one member said: 'You can't beat Yorkshire fish and chips!' In September, Mark Evans from Platon Medical attended to discuss their products and answer queries. The cancer laryngectomee Trust meal at the Savoy Hotel, Blackpool is on 8 December and the Christmas party at the St Ives Hotel, St Annes is on 12 December.

## A Moving Story

Three friends from the local congregation were asked, "When you're in your casket, and friends and congregation members are mourning over you, what would you like them to say?" Artie said, "I would like them to say I was a wonderful husband, a fine spiritual leader, and a great family man." Eugene commented, "I would like them to say I was a wonderful teacher and servant of God who made a huge difference in people's lives." Al said, "I'd like them to say, 'Look, he's moving!'"

(from Still Talking, NSW newsletter)



# News from the Clubs

## 20:20 Leicester to Skegness

The world seems a much brighter place today after yesterday's efforts of thanking everyone for taking part in the 2013 '20-20 Voice' Leicester to Skegness bike ride. It was certainly a day to remember, for many and varied reasons I can tell you, and there is no acrimony to be accorded anywhere, folks, for things that are beyond our control often happen. As chairman I try to foresee all events – unfortunately I can't, but I can do my best to rectify situations and ensure that next year's ride is bigger and better still.

The weather was warm, windy and dull-ish, perfect for bike riding!

I counted 46 heads at Leicester Clock Tower (could have been 45 or 47) and it was quite a sight (pic above) I can tell you as they all prepared to embark on this near 87 mile jaunt. The '20-20 Voice' horn honked – and then fell to pieces! Fine start to an eventful day I must say, but they were on their way at 06.15am, with support car and trailer and several other vehicles in pursuit.

### Fragmentation!

This year was quite amazing as I received text messages to inform me that the '46' had fragmented into groups with some deciding to veer right away from the predetermined route and go via Boston! Quite why, I do not know but they arrived nice and safe in Skegness in time to report to the bar at YATES – well, after all that, how could you possibly miss out on a free pint? Some decided on pure speed and some decided on the non-stop approach. 'Grandad' did his usual sterling job as repair man as three punctures in quick succession were announced and an urgent trip to a bike shop was ordained as someone's bicycle needed surgery! Breakfast was decided upon in Grantham whilst bike shop was being sought and this brought its own problems as I don't think 'Grandad' was even aware that all were not together, so busy was he trying to get the unfortunate biker back on the road. An unfortunate occurrence, but text message directions sorted out our unfortunate 'stranded' who were soon on their way (on the A153) again.

### Drink Stop

As you read this you may think that the day was all doom 'n' gloom – it wasn't. One of our staunch supporters, who was originally on the ride but work prevailed, went ahead and set up our '20-20 Voice' Drink Stop some 20 miles short of Skegness. There she sat, perched on the lip of the boot of her car, displaying her wares for all bikers approaching to espy – bless her! Sakina (and her accomplice Phill), both from the Kinmonth Ward, had driven all the way out to Mareham-le-Fen so as to give the riders a cracking boost (liquid wise) after nigh on 70 miles of pedalling. However, it transpired that about eight of the riders had already gone steaming through the '20-20 Voice' Drink Stop before the team had even 'set up shop' so they completely missed out on this brilliant innovation! So we now know that different riders have different levels of ability – something we shall also address next year.

Sadly, one of our riders sustained a leg injury so, after a few frantic text messages, we ascertained exactly where they were



Leicester Clock Tower 06:00 hrs

and sent a '7-seater' taxi to collect them and their bikes and get them to the finish line. There is never a need for any panic as we would never leave anyone stranded in the 'middle of nowhere', for the safety of our willing combatants is always paramount. Our 'support car and trailer' was actually in Skegness when the call came through and 'Grandad' was blissfully unaware (horrified actually) that anyone was behind the main group that he had faithfully 'followed in'. Apparently the mix-up occurred in Grantham whilst breakfast was being eagerly consumed, punctures were being sorted and bike shops were being located – just one of those unfortunate incidents that blight life sometimes, but all ended well.

### Remarkable Timings

I received some remarkable timings yesterday from our riders: Paul and Ben hit the clock at 4hrs 32mins (staggering speed!) Phil and Steve managed 4hrs 55mins while others managed a few minutes over the 5hr mark – incredible riding, boys!

### Pimms & Certificates!

So, next year we need to be aware that many riders will not only look upon this year's ride as a fund raising activity but also as a personal speed challenge – and why not indeed? I already have names for the '20-20 Voice' '100-up' Skegness Bike Ride as people are excited by the challenge, want to create a 'personal best' time and want to raise funds for a (quote) 'damned good cause'. I've named it the '100-up' because this is something that is growing rapidly, it is a 'damned good cause' for we are not telling people we simply want more money to find cures, we are actively giving head and neck cancer sufferers the chance of early diagnosis thus earlier treatment. But the fact that we are supplying equipment that detects cancer early is the bonus which means our cancer experts can operate earlier and remove the cancerous tissue before major removals (like voice-boxes) are needed. If we can save one person from losing their voice-box then we will have done our job!



Phil Johnson