

# CLAN

THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS NEWSLETTER

Issue No. 123

December 2012

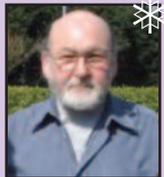
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poems, letters and views

### President's Christmas Message



It is that time of year again when I sit down to write my Christmas message.

It seems to me a very short time ago that in 2005 I sat down to write my first President's Christmas message and I am now writing my last Christmas message as I am standing down as president in May. Before you all start cheering, you are not getting rid of me. I will still be very involved with NALC. May I take this opportunity to say a heartfelt thank you to Vivien, Kerry, the officers and all our members and friends for their support over the time I have been President. It only remains for me to wish everyone a very Happy Christmas and above all a Healthy New Year.



Ivor Smith  
President

### Christmas Crackers

*At a Propane Filling Station:  
"Tank heaven for little grills."*

*At a Radiator Repair Shop:  
"Best place in town  
to take a leak."*

*Still Talking NSW Newsletter*



## A WORD FROM THE EDITOR

### FOOD FOR THOUGHT



Don't you find Christmas comes around so quickly once you're retired? (If you're not yet retired, you're probably still paying for last Christmas!) This year, the family has new Christmas jumpers so we're ready for anything! We're sure that many clubs will have had their Christmas meals and hope they went well. Talking of food – the Editor and wife have recently returned from a three week cruise of the Mediterranean (don't worry – it wasn't on expenses!) so we have enjoyed a considerable amount of fine dining. One passenger we met had been on a 74 day cruise and admitted to putting on over three stone in weight. He said he had had to buy new trousers to cope! We also heard the familiar sound of a Servox and discovered a laryngectomee, John, with his wife, Shirley. You can see the photo inside.

### New NALC Website

On our return, there was a visit to NALC HQ for the launch of the new, improved NALC website. From now on you can download copies of *CLAN* and email them to friends, family and enquirers as you wish. They ran special computing classes on the cruise and many people enjoyed getting to grips with the new technology for the first time. If you haven't yet cruised the internet, why not give it a go? Many libraries now advertise classes for beginners. Our local library allows you to borrow books and read them on your computer.

So we hope you enjoy this issue of *CLAN* and have a wonderful Christmas and New Year. And don't forget to send us news of how your club celebrated!

*Ian Honeysett*  
Ian Honeysett (Editor)

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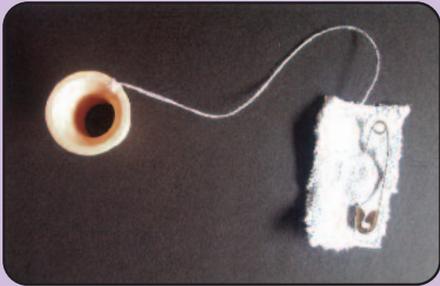
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*The views expressed by the contributors are not necessarily those of the Editor or NALC. Great care has been taken to ensure accuracy but NALC cannot accept responsibility for errors or omissions.*

**Deadline for issue No. 124: 1 February 2013**

## By a Thread

Suzanne McEvoy met Alex McGuigan at the Laryngectomy Information Day in Belfast in October and mentioned her method of securing a stoma button to the wearer's clothing as twice her husband had managed to push his button down into his trachea – and once down into his lungs. She said hers was not an original idea but she found it in a book and then refined it. The idea is to secure the thread from the stoma button to a piece of material rather than directly to a safety pin. The photo explains all.



### Hear, hear?

**Doctor:** "What seems to be the trouble?"

**Patient:** "Doctor, I keep getting the feeling that nobody can hear what I say."

**Doctor:** "What seems to be the trouble?"

## Goodbye Sandy

Sadly we said goodbye to a dear friend and fellow 'lary', (Alexander) 'Sandy' Robson whose funeral was held at Loughborough Crematorium on Tuesday, 31st July. 'Sandy' joined our unique 'club' in 2005 and certainly lived life to the full for the next seven years.

His wishes were that people donated to '20-20 vision of VOICE' Cancer Appeal instead of 'wasting money on flowers' and his generous wishes have raised in excess of £655 for the appeal. 'Sandy' wanted to help those of us that are to come, for he knew that the vital equipment we are aiming to buy will possibly save future head and neck cancer sufferers from losing their voice.

We send our sincerest thanks and condolences to his wife Phyllis and his children Mandy, Annette and Martin. Thank you, Sandy, may you rest in peace my friend.

*Phil Johnson*



## Laryngectomy Support on Facebook: A unique way to give support

When I started a Laryngectomy Support group on Facebook in 2009, I did not realise the powerful impact the group would have. The Laryngectomy Support group started in September 2009. Having had some experience with managing online support groups, I thought Facebook would be an ideal location for an international Support Group. The goal of the group is to get people affected by laryngectomy together; to provide support to each other and exchange ideas and tips.

I started by inviting a few clinician colleagues (people I knew could spread the word to their patients). The first few months went by and... nothing much happened. Then, slowly I started getting requests to join the group. This support group has now grown to 165 members and is currently the biggest support group for Laryngectomees on Facebook. We get about two requests per week from other people who want to join. The group is truly international, with members from all over the world.

We have a few renowned members, for example Dr Itzak Brook, who has written a book on laryngectomy; and regularly gives talks at international conferences and meetings. We have members who give regular updates on their condition and members who just want to read the tips that other members give. We have people posting on the ways the laryngectomy changed their lives, positives and negatives.

### Familiar Faces

Visiting the group is like visiting family. You see familiar faces, and you get to hear what happened in other members' journeys through life. You get to offer advice and support; and when you need an answer, you can just pose a question to the group and you will get a multitude of responses back. Sometimes topics are very serious, and other times about less serious, more general topics. Often members bring humour to the group. Through the postings you truly get to know the personalities of the group members.

Facebook has a unique way of allowing members to view each other's comments and reply in a conversational way. Regularly, a topic gets discussed in detail, with people adding links to YouTube and



other useful resources. This way of conversing in the setting of Facebook has taken laryngectomy support to a new level.

One thing that surprised me about the group is the mix of membership. There is a proportion of young members of the group who have a parent or grandparent with a laryngectomy. It is great to see that these young people who have concern for their parent or grandparent can get free support in such a setting. There is also a proportion of the membership who are friends of persons who had a laryngectomy (a group of people who have traditionally not received much in the way of support or information). Of course the largest proportion of the group consists of people who have had a laryngectomy, or their partners. It is refreshing to see such a variety of ages and reasons for joining the group. It is a reminder of how laryngectomy affects not only the person but also everyone who knows that person; and that support and education is needed on many different levels. I think this is truly an inclusive group; something that results great discussions on the forum.

### 300 Target

My aim for the group is to continue excellent support to our members and to increase membership to 300 people by the end of 2013. I believe that the support group will become a new platform for people affected by laryngectomy all over the world. We will be able to support members and their local efforts with international drive and in a very special way. Thank you to all the group members for your willingness to share your ideas and tips with the world, and to provide amazing support to each other. Welcome to all future members, the sky is the limit!

*Louise Pothier  
mail@louisepothier.com*

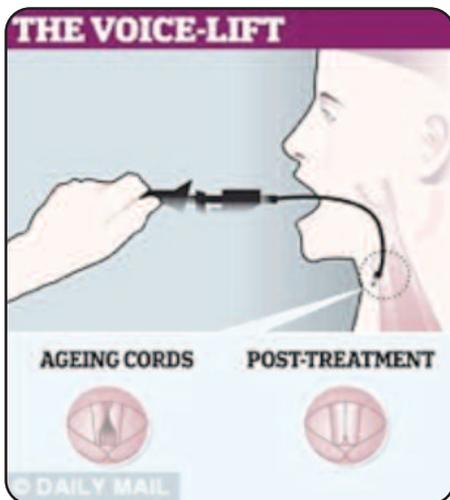


## Boom in 'Voice-Lifts'

This article was published in the *Daily Mail* on Monday, 17th September 2012 by Fiona Macrae

'Voice-lift' surgery is becoming the latest must-have for those keen to turn back the clock. Ear, nose and throat surgeons say the operation to restore youthful tones can boost the confidence of business people who believe their authority is eroded as their voice ages. And with more people working well past retirement, the voice lift, which costs up to £6,000, is expected to become increasingly popular.

The doctors treating them, known as phonosurgeons, claim it reduces the reediness in the voice. Our vocal cords need to be pliable to vibrate thousands of times a minute, producing the puffs of air that help us form sounds.



**Diagram:** It involves injecting the folds of the vocal cords with fat removed from the stomach to bulk them up and boost the strength of the voice. But, like other parts of the body, they age, becoming thinner, and so do not close properly, which affects the voice. Various substances are used to plump them up and bring them closer together. John Rubin, a consultant at the Royal National Throat, Nose and Ear Hospital in London, advocates injecting stomach fat into the vocal cords to bulk them up and boost the voice.

Some surgeons use collagen or other fillers more commonly used to plump up lips, but these can make the vocal cords too stiff or work only in the short term, Mr Rubin said. He told a Sunday newspaper: 'The biomechanical properties of fat aren't that different from the vocal cords. Fat has a high water content, so half of what is injected disappears within 36 hours. The rest stays put and will be effective for [up to] 18 months.'

In men, the voice begins to show signs of ageing from about 30-years-old. For women, it can come after the menopause or even much later. This weakening – known as glottic insufficiency – happens when the vocal cords lose the muscle tone that enables them to close properly. Sufferers often complain that their voice becomes reedy and lacks the convictions needed for situations such as board meetings.

## Proton Beam Therapy

Proton therapy is a type of radiotherapy that stays focused on the tumour shape and delivers only low doses (and therefore side-effects) to surrounding tissues.

There are two groups of cancer patients who stand to benefit most from this: those who require



doses to be increased gradually to very high levels, and those whose cancers are surrounded by tissues, such as the brain or eye, which might be damaged severely by conventional radiotherapy. The latter group includes patients with head and neck cancer, including laryngeal cancer. The Massachusetts General Hospital in Boston, USA, was the first place to develop this treatment, and there are now several centres around the world. The UK Department of Health announced its intention to establish two-three such centres here four years ago, and a competition resulted in University College Hospital London and Christie Hospital Manchester being chosen as sites.



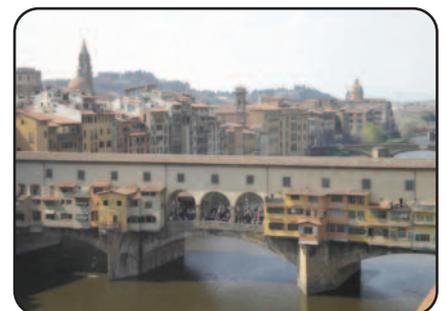
[www.webwhispers.org](http://www.webwhispers.org) always has a fund of interesting articles. As winter draws on, take a break and read Jack Henslee's account of his holiday in sunny Italy.

Many of my travels involve visits with other laryngectomees or laryngectomee organisations around the world whenever possible. We only allowed ourselves three days in Rome since Florence was the primary destination and we truly got the most out of it. The first full day was just a self guided walking tour through the streets of Rome where we visited Trevi Fountain, The Spanish Steps, a wonderful park, and did general sightseeing. All of which was free so that was really good. The next day we did the Vatican.... Wow! This is a must see whatever religion you are. The history, the art, the buildings, and St Peter's to go with it. I went to



Rome for one primary reason. To see what I think is the greatest work of art in the world... The Sistine Chapel! I was definitely not disappointed.

On the fourth day we headed to Florence via train. This was so simple with express trains running almost every hour and the trip was only about two hours. As in Rome, Florence is a great walking city and you can see most of everything within a 20 minute walk. The highlight for me is of course the Uffizi Museum which is rated one of the top five in the world. Sculpture is everywhere and of course the "David" by Michelangelo is superb. Aside from seeing the museums, the churches, the architecture, shops (famous for handmade leathers), the many restaurants, and galleries we also took a bus tour to Siena and San Gimignano. Siena is famous for its beauty and rightfully so. A small town with very limited traffic that is a well preserved centuries old treasure. It does have some fairly steep hills and the only way around is walking, so take that into account.



# Emergency, Emergency

NALC provide a range of emergency items as follows:

## Emergency Card

This is a credit card size card in red and blue explaining the emergency procedure for laryngectomees.



## Emergency Car Stickers

Self-adhesive orange stickers for display on car wind-screens. Gives instructions that mouth-to-neck resuscitation should be given, in case of an emergency.



## Emergency Wristbands

Red rubber wristbands with the words – Resuscitate Via Neck Stoma Neck Breather!



All emergency products are available free of charge from NALC head office.

152 Buckingham Palace Road  
London SW1W 9TR  
020 7730 8585  
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# TEP Revisited

The TEP (Tracheoesophageal Puncture) has been around for over 30 years and many patients have punctures that may indeed be that old. I have noticed over the years that punctures sometimes have a life span of their own and occasionally need to be redone when they fail to work effectively and become difficult to maintain. I have my own thoughts as to why the punctures might wear out. First, occluding the stoma with a finger constantly moves the prosthesis in its tract. This can cause granulation tissue to develop, both on the stoma side and on the oesophageal side of the fistula. This granulation can make the prosthesis difficult to insert and properly maintain and can lead to decreased voicing. Acid reflux and the bacteria associated with saliva and sputum also enhance granulation formation.

Along the same line, I have seen several fistulas actually migrate up and out of the stoma so that they become completely ineffective. My only explanation for this is the continued manipulation over the years pushing the tract and the prosthesis up and out of the stoma. Lastly, I can recall two patients who developed swallowing difficulty from an erosion of the oesophagus caused by the tip of the speech prosthesis.

## What To Do?

So what do we do when the granulation tissues gets too bad, the fistula migrates out of the stoma, or an erosion develops in the oesophagus causing difficulty with swallowing? The first thing we do is stop using the prosthesis for a while and give the area a chance to settle down. In the case of laryngeal granulation tissue we will replace the prosthesis with a small catheter and deal with the granulations. This may involve removal with a LASER or cautery and then several week of healing before replacing the prosthesis. This applies only to granulation in the trachea.

The problem in the oesophagus is a little different matter. For oesophageal problems like granulation or erosion and for fistulas that migrate out of the stoma we often have to disregard completely the current fistula, let it close and come back in a month or so for a re-puncture. This lets everything heal and creates a more controlled situation for a better placement. Usually the fistula will close once the prosthesis is removed, but it may be necessary to close the tract with an outpatient procedure before the repeat puncture can be done.

After the repuncture, we basically start over with resizing as the tract matures.

Glenn E. Peters, M.D., F.A.C.S. Director, Division of Otolaryngology – Head and Neck Surgery University of Alabama, Birmingham, Birmingham, Alabama, USA. (from *Still Talking*, NSW Newsletter)

# No Answer to That

In a small business office they have an answering machine that instructs callers to leave their name and address, and to spell any difficult words. Early one Monday the secretary was reviewing the weekend messages and she heard an enthusiastic young woman recite her name and address and then confidently offer, "My difficult word is reconciliation. R-E-C-O-N-C-I-L-I-A-T-I-O-N."

*Still Talking NSW newsletter*

# Chicken & Mushroom Casserole

Here's a hearty meal to ward off the winter cold. It's also a good way of introducing meat into your diet as the chicken is soft, with the onions and tomatoes making a flavourful sauce. The wine can be omitted and replaced with more chicken stock if you prefer.

## Ingredients

- 4 to 5 tbsp olive oil
- 3 ripe tomatoes, peeled and chopped
- 1 onion peeled and finely chopped
- 3 to 4 tbsp flour
- 750g mixed mushrooms, cut into thick slices
- 750g skinless chicken breasts, sliced into thin escallops
- 250ml dry white wine
- 250ml good chicken stock
- Sea salt and ground black pepper – to taste

## Method

Coat the chicken in flour and season. Heat a little oil in a casserole, add the chicken and fry quickly to brown. Remove the chicken from the casserole. Heat 3 tbsp oil in the casserole then add the onion and cook on fairly high heat until softened. Add the tomatoes and stir for a few minutes until they become jammy, remove the onion and tomato mixture keeping it

separate from chicken. Add the remaining oil and the mushrooms and cook on high for about 5 minutes. Return the chicken to casserole, add white wine, boil and simmer for about five minutes. Add stock, onion and tomato mixture to the casserole. Season with salt and pepper. Cover, bring to boil and then simmer for about 20 minutes until chicken is cooked and tender. Serve with rice and green vegetables. Serves 4.

*Wendy Owen*

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.



# Skegness Charity Bike Ride Report

On Saturday 18th August, 2012, seventeen eager cyclists lined up at Leicester clock tower with the intention of cycling all the way to Skegness clock tower. Their intention was to raise money for the '20-20 vision of VOICE' Cancer Appeal which has been formed with the sole intention of providing essential medical equipment for head and neck cancer patients nationwide.



*Leicester Clock Tower 6.00am – all wearing '20-20' sashes*

As Chairman I had the privileged to wish them well, to be safe and to start them off with the '20-20' Air Horn. What an awful racket that thing made and as they pedalled away at 6.07am.

We soon received a text message "seven miles from Grantham", then "two miles from Sleaford". 'Team '20-20' were rockin'!

However, the weather was hotting up considerably, they could not possibly maintain that pace, so we decided to take the same route to Skegness as our cyclists just in case any of them needed a bit of four wheeled comfort. We started passing then approximately 11 miles from Skegness, some were cherry red from the heat (not to mention the effort involved), some were pushing up an endless hill and some were simply sheltering under some trees and out of the sweltering heat. If I'd have been in a large van I'd have

offered to pack them all in and dump them off again a mile from Skegness! But then again, I know that none of them, no matter how shattered they were, would have let me do that for this was no longer just a matter of raising money for '20-20 vision of VOICE' Cancer Appeal, this was now a serious matter of pride. At this point I must advance my sincerest thanks to our support car that 'tailed' the slowest rider and was also immediately on hand for puncture repairs, etc. A vital job very well done indeed! Thank you 'grandad' on behalf of all involved.

We (Tina and I) arrived at Skegness about 2pm and immediately set up the banner on the sea-front railings and set about 'tin rattling' for donations. After about 30 minutes of this, with very little response, we were approached by a certain gentleman that I recognised but couldn't place. It was none other than Cllr Mark Anderson, His Worshipful, the Mayor of Skegness, whom I had contacted but wasn't totally sure would hang around as I could not give him a specific arrival time.



*Some of the gang with Lord Mayor, Mark Anderson*

He kindly introduced me to the manager of "Yates" on the sea front where we arranged for a refreshing, wet, cold and welcoming beverage for our intrepid riders (and all concerned) – who, as we

were arranging such, went pedalling merrily by the place at 3.27pm! [9hrs, including breaks, what a marvellous achievement for non professional cyclists – not a Bradley Wiggins among them!] They were soon recalled and treated to a drink, each cyclist being presented with a certificate of recognition for the fantastic feat they had performed.

And it was a fantastic feat, there were no professional cyclists among our number, certainly no Bradley Wiggins, only normal (I think!) everyday people with willing hearts and a will to help our small but rapidly growing charity.

The boys and girls have raised approximately £2,500 with this fantastic effort and I single no particular person out as they were all stars on the day – the hottest day of the year to boot! A short but powerful speech (and a plea) by the Mayor involved a couple of buckets being passed round with Skegnessians and visitors alike kindly adding to our funds (I will announce a final figure when all the promised donations are in). It seemed that the Mayor's prompting is like 'Double Diamond' used to be – it worked wonders! I pass on my sincerest thanks to 'His Worshipful' for taking time out to welcome our leviathans of pedal power to Skegness and his efforts to increase our funds.

Everyone was exhausted, but happy that the task had been completed and, more importantly, I am almost sure that we have now passed the £5,000 mark. Finally I must thank everyone who helped to make this massive day work – and that means all of YOU out there. I can only arrange things but it is all of YOU that create these wonderful moments... Thank you so much, every single one of you.

*Phil Johnson, Chairman  
'20-20 vision of VOICE' Cancer Appeal*

## My Sat Nav

I have a little Sat Nav  
It sits there in my car  
A Sat Nav is a driver's friend  
It tells you where you are

I have a little Sat Nav  
I've had it all my life  
It's better than the normal ones  
My Sat Nav is my wife

It gives me full instructions  
Especially how to drive

"It's thirty miles an hour," it says  
"You're doing thirty-five"

It tells me when to stop and start  
And when to use the brake  
And tells me that it's never ever  
Safe to overtake

It tells me when a light is red  
And when it goes to green  
It seems to know instinctively  
Just when to intervene

It lists the vehicles just in front

And all those to the rear  
And taking this into account  
It specifies my gear

I'm sure no other driver  
Has so helpful a device  
For when we leave & lock the car  
It still gives its advice

It fills me up with counselling  
Each journey's pretty fraught  
So why don't I exchange it  
And get a quieter sort?

Ah well, you see, it cleans the house,  
Makes sure I'm properly fed,  
It washes all my shirts & things  
And keeps me warm in bed!

Despite all these advantages  
And my tendency to scoff,  
I only wish that now and then  
My Sat Nav would turn off.

*Sent in by, but not written by,  
Clifford Hughes*



## NALC Launches New Website

Your intrepid reporter/editor attended the unveiling of the new NALC website which should be fully up and running from December 12. Among other improvements, it should hold electronic copies of *CLAN* (which individual clubs might wish to make available on their websites). Here you can see two screen prints showing the Welcome page that will greet you when you log on and the *CLAN* page where you will be able to download copies from the last two years. The web address is unchanged. The photo shows those most involved in the venture.



Left to right: Stuart Rodgers (website developer at Seventy 78), Alex McGuiggan, Malcolm Babb and Andy Cage.



## The Colours We See

We take all colours for granted,  
as we see them every day,  
our world so lovingly painted,  
every hue in sweet array.

But what of those, made cruelly blind,  
or have a mist-iness, there to stay,  
how could nature, be so unkind,  
when to those, their world is grey.

A world without colour,  
would be dim without their light,  
sad flowers would gasp for colour,  
if the sun stopped shining bright.

The meadow grass, so green and calm,  
would be grey with sadness too,  
and golden corn, their stately charm,  
would vanish in a grey-ish dew.

And trees so bare, without green leaves,  
would look odd to say the least.  
Like some old coat, without its sleeves,  
not a beauty, but a beast.

No bright yellow sun, to make us warm,  
no blue sky, that we see above.  
No rainbow there, to follow the storm,  
showing colours that we love.

There are thousands of colours,  
that we see every day,  
because God gave those colours,  
to help lighten our way.

So spare a thought, for those of us,  
whose world is only grey.  
So live your life with little fuss,  
and be thankful every day.

*Len A. Hynds  
(two cataract ops coming up...)*

## National Cancer Support

We've received a copy of the NCS Newsletter which reports on their annual conference: "With fewer than 120 delegates, this year's conference was much smaller than usual. But that didn't stop it being successful – in fact, many of you felt that this actually improved the atmosphere. Besides, through those 120 delegates, at least 28 self-help and support organisations were represented, with people travelling from many regions in the north of England, from London and the south-west, the Isle of Man, Wales, Scotland and Northern Ireland (and even Cyprus). So we really can say that Manchester 2012 saw a truly National Conference of Cancer Self-Help Groups. We hope this newsletter will be a happy reminder of the experience for those of you who attended. And if you didn't, let's hope it encourages you to come along next year. But don't forget that NCS isn't just about the annual conference. It is about supporting you in your involvement and work with cancer self-help, enabling you to link up with and learn from each other.

So, check out our new website: [www.nationalcancer.org](http://www.nationalcancer.org) Join us on

Facebook: [www.facebook.com/NationalCancerSupport](http://www.facebook.com/NationalCancerSupport) E-mail us with your news, photos, updates and ideas [natcancernews@gmail.com](mailto:natcancernews@gmail.com) Let's network!

One delegate, Pam Cartwright (a physiotherapist), records her experiences of attending. Pam herself has completed medical treatment for breast cancer but wanted to know what else there was to help her.

She had been reading about holistic therapies, then, just the day before the 2012 conference was due to start, she met Fiona



Shakeela Burns, a Herbal Therapist and one of the speakers this year, who told her she should come along. So Pam downloaded the information from the NCS website and set off for Manchester!

She is very glad that she did. She had a 'fantastic time' and says that her questions have been answered and fears allayed. She has made many contacts to follow up and particularly enjoyed the informative Gerson Therapy workshop. She is concerned, however, that, given the importance of nutrition in dealing with cancer, the food in the restaurant could be of a healthier quality. She also thinks that the conference should last longer.

**In a Veterinarian's waiting room:  
"Be back in 5 minutes. Sit! Stay!"  
(Still Talking, NSW Newsletter)**



## I Love My Stoma Cover

Here at the NALC HQ we aim to help every single person who comes into contact with us. Whether it be just a small snippet of information, a literature pack or a DVD, we really hope whatever help we offer can make even a small difference to the life of a Laryngectomee. So when we received an email from a gentleman in Uganda, asking for advice, we didn't hesitate to pack up some info along with a DVD and send them to him. We have now been communicating with Emmanuel for several months, adding him to the mailing list and also sending him some spare stoma covers that we had in the office. He is very grateful for the items that we send and looks forward to receiving his copy of *CLAN*. He has recently sent an article along with his photograph and we felt that it would be lovely to share this with our readers.

"I love my involvement with NALC, I am now

among the proud person whom you can never be released of! A person who each day and night thinks of his endless life younger as 28 years old. As of now, I am very grateful to be a family of laryngectomees for nurturing me a promised generation of the next 60 years to come; since my operation in September 2009, I was stigmatised on how I will fit myself in the youth community plus my dream to be educated person like others. But where all this happiness comes from? Hey whenever I wear a bib (stoma cover) to protect my chest, I feel much comfortable in the community and do well my own work.

"Do you know the surprise part of stoma cover? People in the community can recognise you that you're laryngectomee. You can imagine that I have completed my three years degree course of computer science at Kyambogo University and now



its four years since my operation. And my smile now in Uganda perhaps in the whole world is the best supportive facilities and strength ideas received from NALC. God bless NALC abundantly."

*Bychance Emmanuel  
Kyambogo University, Uganda*

## Dr Itzhak Brook on YouTube

You can see and hear Dr Itzhak Brook lecture on: *A Physician's Persepective as a Throat Cancer Patient* at: [www.youtube.com/watch?v=Z3gDL3sozTg&feature=youtu.be](http://www.youtube.com/watch?v=Z3gDL3sozTg&feature=youtu.be)

This was the **J Conley Medical Ethics Lecture** to the Annual Meeting of the American Academy of Otolaryngology in September 2012. It lasts just 20 minutes. For those of you without internet access, here are some of the points he makes:



- Throat cancer strikes at the most basic need – the ability to communicate and interact with others. Losing this is a devastating experience.
- Suddenly I had to deal with my own mortality... my fear and uncertainty for the future. My relationship with others was changed.
- Although I had been a physician for 45 years, I knew very little about the different approaches available. My state of mind was so anxious, I couldn't be a good decision-maker.
- My main interest was to get the cancer out as soon as possible. I prefer the truth even if it's not so rosy. When I awoke with tubes and no voice, it was so different to everything they had told me.
- (As a physician) spend time with the patient and tell them again and again, "nothing is more powerful than a hug..." not necessarily a physical hug but an emotional one. Getting to meet laryngectomees before surgery was most helpful.
- Allow the patient to talk again as soon as possible even with an electro-larynx.
- The team approach is important – surgeon, nurse, speech therapist, social worker, nutritionist (working together)
- The patient worries: "Am I cured? Is it recurring?" There is no substitute for the follow-up.
- As a physician, remind the patient that things will get better – the swelling will go down and your speech will improve.
- A major challenge is depression – you're more bottled-in as you can't express emotions as before and even facial expressions change. A way to overcome this is to remind yourself to set an example to your children not to give up in adversity, but to find your purpose for living
- I experienced life differently as a laryngectomee: I learned to economise with words; no need to wear ties again; no more snoring; or catching colds.
- Everyone can see our cancer – we are a sign that lives on despite cancer!

## Just Cruising

The Editor and his wife decided to take a Mediterranean cruise this October. And whom should they meet but John Jones and his wife, Shirley. John had his laryngectomy in May 1986 at the old Radcliffe Infirmary and, after a period of convalescence, was retired from the BBC. They left the Oxford club when Ken Whitley retired from his role there. They had taken part in all the club fund-raising activities for the ENT unit. They found the annual bazaars great fun as well as them raising a great deal of money and Shirley made knitted figures to hang on Christmas trees and made a large decorated Christmas cake to raffle. Since retiring, John has continued to lead an active life – which will, he hopes, give encouragement to others who have just had, or are about to have, the operation. And that active life includes, of course, cruising – as you can see from the photo below.





# News from the Clubs



## Plymouth Club

A disappointing handful of Club Members turned up for the AGM at Derriford on Monday, 11th October 2012. Geoff Read chaired the meeting and reported that the PLC now had 17 members and many Friends! Two more joined on the day! Sadly, one of our founder members passed away earlier this year. Dave Edwards was a popular member of our group, always with a cheerful smile. He will be missed by all. Jean Read told everyone that the Club had found it unnecessary for Members to pay the sum of £1 at every meeting so this was stopped. The Club will still ask all its Members to pay an Annual Subscription of £5 each and that will be due on 1st January 2013.

The Club was fortunate in March 2012 to receive a monetary grant from the Devon Community Foundation. The Club was pleasantly surprised in March 2012 to receive the sum of £110 which was passed to them by Maggie Jarvis and Claire Percival. This sum was the proceeds from a Quiz Night for their benefit. Geoff pointed out that the Club had also received a monetary award from The Plymouth City Council for the AGM and the Information Day. They awarded them £250 to help celebrate the 2012 Plymouth Older People's Day. It was just as well that the majority of members are over 50 which apparently was the qualifying age! The Club used this money to help pay for the AGM refreshments and buffet lunch. Geoff added that Platon Medical, Kapitex and R Care (Mid) also contributed some cash towards the cost of the day's refreshments.

The afternoon session included a talk by Trevor Phillips, a Clinical Specialist (Physiotherapy) from Derriford Hospital. The talk was of especial interest to laryngectomees as it was all about Managing Your Chest and Breathing After Laryngectomy Surgery.

The audience was then divided into two groups:

- **Group A Discussed the Carer's Perspective:** What is it like being the relative/carer of someone who has had the surgery?
- **Group B Discussed the Patient's Perspective:** What is it really like to

## The Speakeasy Club, Cornwall

Club members met at Devoran for a soup lunch prepared by Janet and her friends Stef and Clair. Unfortunately their numbers were very small as several people had to drop out, several at the last moment. Their car boot sale raised £32. Their newsletter reports that Malcolm Merrett is putting together a website for Head and Neck groups and will be happy to include the club when it gets going. For their Christmas lunch they will have a speaker to entertain them. Maurice Roberts is the first Cornish President of the Budgerigar Society and is giving a 20 minute illustrated talk about these fascinating little birds.

**At a Car Dealership: "The best way to get back on your feet – miss a car payment."**  
*Still Talking NSW Newsletter*

## Thank-you

A teenager who had just received her learner's permit offered to drive her parents to church. After a hair-raising ride, they finally reached their destination. The mother got out of the car and said, "Thank you!" "Anytime," her daughter replied. As the woman slammed the door, she said, "I wasn't talking to you. I was talking to God."

*Still Talking Newsletter NSW*

## Paragons

**"To all of you paragons of virtue who don't drink or smoke, at least when you die, it won't be from anything serious!"**

*Dave Allen*

*(quoted by The Plymouth Club newsletter)*

experience having surgery and living with the after-effects?

The day culminated in a forum of open discussion. An agreeable and informative day which they all hope will be repeated in 2013.

## The Happy Larrys, Liverpool

Due to their excellent fundraising, the Club were once again able to have a lovely day out at Llandudno (as their photo shows). They were also able to enjoy lunches at The Adelphi Hotel in Liverpool and the Prince of Wales Hotel, Southport as well as several evenings at The Playhouse Theatre.



## The Windpipers, Blackpool

The club had two successful outings: the meal at the Boar's Head, Ripley was beautiful and was followed by a visit to Ripon where the weather was, unfortunately, rather damp. The trip to the Anderton Boat Lift was successful too.

In order to help members get to know each other better, they have started to include member profiles. The first is of Edward Duffy BEM (British Empire Medal). Born in Greenock, Scotland in 1948, he joined the army in 1965 and was posted to Germany where he spent three years. He met his wife-to-be, Jean back in England and they had two children. He was awarded the BEM for his services to Youth. His army career ended in 1988 but he joined the Specialist Territorial Army till 1998. At the same time he worked for Guardian Royal Exchange as a Post Room and Stores Manager. Then, in 2008, he was diagnosed with laryngeal cancer and, as he says, the rest is history.

They also mention that Kevin Garfoot is keen to start a choir. He has been in touch with the Choir Master at Kirkham Grammar who seems to be interested. And their wine raffle raised £18.