

CLAN



THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS NEWSLETTER

Issue No. 122

September 2012

Inside this issue

Conference News 2
Ken Whiley 2

Marilyn Jones 3
20-20 News 3
Verse and Worse 4
Building New Organs 5

Real Life Stories 6
News from the Clubs 7 – 8
Plus lots of other news, thoughts,
poems, letters and views

Deep Down

"The short article about swallowing problems provoked yet another foray into a worse-verse limerick as I reflected on a visit to the Victoria Hospital in Kirkcaldy (the home of Chinwags which meets at the Maggie Centre there).

From deep down inside my oesophagus
Emerged rumblings and burpings
cacophonous;
Is it merely a question
Of acute indigestion?
...Or a plot in the local sarcophagus!

A bit of black humour never did anyone
any harm! And nothing of harm was
found."

Clifford Hughes

Places I've Been

I've been in many places, but I've never been in Cahoots.

Apparently, you can't go alone.

You have to be in Cahoots with someone.

I've also never been in Cognito.

I hear no one recognises you there.

I have, however, been in Sane.

They don't have an airport; you have to be driven there.

I've made several trips there, thanks to my friends, family and work.

I would like to go to Conclusions, but you have to jump, and I'm not too much on physical activity anymore.

I have also been in Doubt.

That is a sad place to go, and I try not to visit there too often.

I've been in Flexible, but only when it was very important to stand firm.

Sometimes I'm in Capable, and I go there more often as I'm getting older.



A WORD FROM THE EDITOR

OLYMPIC MEMORIES



By the time you read this, the Olympics might seem a distant memory but I'm writing this having just witnessed (surely the future Lord) Bradley Wiggins storm to victory yet again. So many inspiring characters. Which brings me to two of our own inspirations whom we fondly remember in this issue: Marilyn Jones and Ken Whiley. Both will be greatly missed. I well remember, when I was searching for items for *CLAN*, the Oxford *Newsletter* which Ken edited would drop on my door mat and I knew I had material enough there for a page or two!

WERE YOU THERE?

And thinking of Olympic/Paralympic memories – were you able to attend any events? And, if so, any memories you can share with those of us who just watched it avidly on the TV? We'd love to hear from you. We've also got a story for you to read on these lengthening autumn evenings: by regular contributor, Len A. Hynds. It's what you might call a Dog's Tale. Happy reading!

Ian Honeysett
Ian Honeysett (Editor)

For all items for *Clan*:

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

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

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

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. 123: 1 November 2012

One of my favourite places to be is in Suspende!
It really gets the adrenalin flowing and pumps up the old heart!

At my age I need all the stimuli I can get!
I may have been in Continent, and I don't remember what country I was in.
It's an age thing!

GNR

Conference News

Royal Preston's Speech and Language Therapy Department recently hosted a very successful Cancer Network Laryngectomy Conference. Over 100 laryngectomees and carers travelled from Barrow-in-Furness, Lancaster, Preston, Chorley, Blackpool and Blackburn to the Marriott Hotel on 11 May 2012. A morning of talks followed by a buffet lunch and opportunity to browse a variety of stalls was organised by Louise Stevens, Macmillan Speech and Language Therapist. She explained that people who have had their larynx or voice box removed, usually through cancer, often feel very isolated and were keen to have the opportunity to meet together for information sharing and support.

Speakers at the Conference were both professionals and patients; Ms S. Penney, ENT Registrar at Royal Preston Hospital, talked about swallowing after laryngectomy. Tom Foot, Doreen Griffiths and Bert Culling (Vice President of the National Association of Laryngectomy Clubs) discussed swimming after laryngectomy. For people who are now 'neck breathers' – meaning they have to breathe through a stoma in their neck after surgery – this can be very difficult and requires the use of a swimming aid. Tom Foot, a laryngectomy patient, was able to give his personal experiences of swimming with the Aqua-Ther swimming aid. Prior to his laryngectomy, Tom had previously been a keen diver, and using the aid has enabled him to return to swimming. Finally, Linda Evans, from Royal Liverpool Hospital, talked about the 'Neck Breathers Project' which utilised Royal Preston Hospital as a pilot site to raise awareness of neck breathers through education and training.

Feedback from the day was excellent with requests to make this an annual event. We are indebted to the attendees, speakers, organisers, representatives and Rosemere for funding, making this a successful and worthwhile patient support day.



Ken Whiley (1922-2012)

Ken was born in 1922 and was the eldest of eight children. In 1940, at the age of 18, he volunteered to join the RAF and, after training as a Wireless Operator Air Gunner, he flew with No. 612 (City of Aberdeen) Royal Auxiliary Squadron, searching for U-boats, E-boats and enemy shipping until the end of the war. He then accepted a temporary commission to remain in the RAF for a few more years. From 1949 to 1951 he completed a course at the RAF Technical College to become a Ground Signals Officer and was awarded a permanent commission. Ken was stationed at a number of RAF stations including stations in the UK, France and Germany – at three of them he was the commanding officer.

In 1971 he received an MBE from the Queen Mother for his services in Berlin. Having served 32 years, he retired in 1973 at the rank of Squadron Leader. He was then employed as Administrative Manager of an Architects & Quantity Surveyors Department at a London Regional Health Authority and then for seven years as principal Administrator at the National Radiological Protection Board, Harwell. Ken was a qualified engineer and was entitled to print a number of initials after his name as he had been elected as a member of the Council of Engineers, a member of the Royal Aeronautical Society, a Member of the Institute of Engineering & Technology and a Member of the British Institute of Management.

Peggy

Ken married Peggy in 1942 and they were married 51 years when, sadly, Peggy died in 1993. They had three sons: first Keith, then Nicholas, who died soon after birth in 1956 in Germany, and thirdly, Howard. They also had three grand-children: Martin, Henry and Amy. In 1996 Ken met Joan, a widow and sister-in-law of his late wife. She was living a lonely life in her flat in Essex so Ken invited her for a weekend to see what country life was like. She enjoyed it so much she stayed. They much enjoyed each other's company and loved going on holidays, visiting relatives and friends. Joan was a great help to Ken and the Oxford Laryngectomy Club for the next ten years until sadly she died in October 2006.

In 1981, Ken developed throat cancer and had his larynx removed. He returned to

work after five weeks and, with the help of speech therapists, his staff and spending two hours each evening talking into a tape

recorder, he was able to converse clearly with an oesophageal voice. Ken formed the Oxford Laryngectomy Club a few months after his own operation in 1982. He had heard about similar clubs elsewhere and felt that this was something badly needed in the Oxford area – and it certainly was needed. In his 25 years plus with the Club, it gained many members: those who were about to have operations, their families and friends. Members came, from people in Oxford and from miles around. The Club went from strength to strength – not only helping those affected with information who were about to have an operation but also as a social club and fundraiser. There were many enjoyable lunches and dinners. These were great not only for meeting members and their families but also raised money through various raffles. That was apart from Bring & Buy sales and other events run by Ken and other members. Substantial amounts have been raised and this has been used over the years to help the Consultants buy much needed equipment, helping individuals affected and refurbishing a relatives' room in the hospital to name but a few.

Ken's health gradually deteriorated and he moved from his home in Oxford to assisted accommodation in 2009 in Great Dunmow. He had always wished to return to Essex to be near his brothers and sisters. He enjoyed for some time trips around Essex rediscovering 'old haunts'. After a period in hospital in 2010, he moved to live in a nursing home until his death in January 2012. Ken will be remembered by his brother and sisters and all his family as someone who always considered others, was extremely charitable, forgiving and always doing so in a quiet and unassuming way.



Keith Whiley

Marilyn Jones

I had my laryngectomy in 2007. As I did not know anyone but my son and his friends, I was very grateful to have met Marilyn Jones. After being diagnosed I wanted to meet a fellow laryngectomee prior to my surgery in order for me to understand everything. Marilyn became a wonderful friend to me. Without her I would have been very lonely and extremely depressed. She really helped me to get through the tough times.

Introducing me to NALC was one of the best things that Marilyn did for me. I have met lovely people who have inspired



me to realise that there is life after a laryngectomy. Through meeting Marilyn I now give talks to student speech therapists at The City Lit University in London during the autumn months. I have also given talks to head and neck nurses so that they can understand the needs of a laryngectomee. Marilyn was very dedicated to NALC and told me if it had not been for NALC she too would have felt the same as I did in the beginning. She was so devoted that she would promote NALC to any new laryngectomee that she met. She was so very kind hearted and was always there to help me.

When she became ill, it was very sad as she could not cope being with anyone except her immediate family as she didn't want to upset her friends and associates. I had to respect her wishes although I missed her terribly and still do. Her passing was very sad and has left me with a terrible void in my life. I will always be a member of NALC as I know that is what Marilyn would want.

Gloria Tuck, UCLH Club



On 28 July the intrepid 'Stoney Stanton Stompers' took on the '20-20 Walk the Talk' Cancer Appeal 20 mile walk to raise valuable funds for the vital equipment needed for head & neck cancer patients. The four lads, all from Stoney Stanton, have adopted '20-20 vision of VOICE' and say this will now be an annual event to raise funds. Left to right: Alex Clowes, Andy Landers, Mark Domagala and Steve Postlewaite.

They raised about £500 in sponsorships. The trek took them seven hours, including necessary 'pit stops' to refuel (as above) but they all reported thoroughly enjoying the day.

Phil Johnson, Leicester Club

20-20 News

The Vicars & Tarts Night finally realised £161.50 after all the pennies etc and 'bar tips' were added up, so the ladies of the Wokingham branch did extremely well considering that it was based on numerous raffle prizes only!

Having just read the Jaqueline Gold story (Anne Summers) I have realised that '20-20 vision of VOICE' Cancer Appeal needs 'Wokingham's' all over the country; ie supporters/volunteers in different regions so that we spread the word about head & neck cancers to more people, hold more events and thus get more funds coming in – we cannot get the proper charity status until we can prove we collect at least £5,000 per annum.

The new website is under way and has the obligatory 'donate' button and we now have a '£counter' on the site as well which I can update when necessary but we need more helpers – which is where, I hope, *Clan* can help us out a bit.

Our aim is not simply to buy the Rhinolaryngoscope for my local hospital (LRI) but to accumulate funds for all sorts of necessary equipment for all ENT cancer units – nationwide. So we are not simply a one trick pony – I want this head & neck charity to go on long after I've gone.

Can *Clan* support us with wordage and see if we can find some willing souls around the country who may be prepared

to help others suffer the same as we do – maybe even prevent quite so much suffering!

Visit our website at:

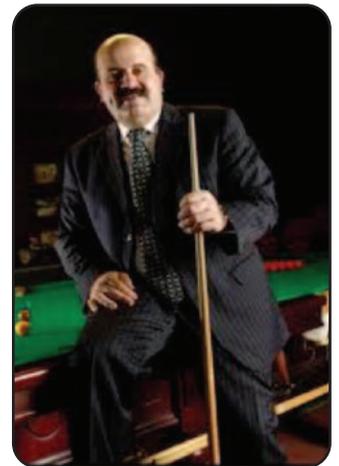
www.2020cancerappeal.org

The '20-20' Cake Sale at the Leicester Royal Infirmary raised a magnificent £150.70. We were there a bit longer this time as the 'fabulous Baker girls' provided an enormous choice of delicacies to tempt the tastebuds. We are aiming to hold the next '20-20' Cake Sale at the end of August

'20-20 vision of VOICE' Cancer Appeal are truly delighted to announce that local snooker star and old friend Willie Thorne has agreed to become our Patron. 'Mr 147' himself still has a busy schedule, what with coaching, TV presenting and after dinner speaking but knows only too well what cancer can do, having lost his beloved brother Malcolm last January. Willie has seen what we are trying to do and applauds our efforts.

We have more events planned but what we really need is 'agents' in various parts of the country. Do you have a few hours to spare? Might you be interested in helping head & neck cancer sufferers all over the country? You don't need to stress yourself out as we will provide you with everything you need to get your fundraising underway in your area. Check out the website at www.2020cancerappeal.org – are you sure you can't help?

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



Verse and Worse or The Therapeutic Value of Laughter

Len Hynds' verses in the June edition of *CLAN* have inspired me to put pen to paper (or two fingers to keyboard!). I visited a Head and Neck Cancer Nurse when I became aware and anxious about what felt like a muesli-like growth on my tongue. The last thing I wanted was cancer of the tongue. She took a look, giggled, and then explained that it was a harmless fungal infection – common in neck breathers.

*The praises of nurses I've sung;
They're caring, compassionate, young.
But Oh! The disgrace
To be told to my face:
"Hey! Cliff! You've a brown hairy tongue!"*

A year or two after my laryngectomy operation, I had both knees replaced at Perth Royal Infirmary. To nurses and physios, I sent the following:

*The wonderful nurses of Perth
Go at it for all they are worth.
Now, don't get me wrong:
Not "wine, men and song"
But care, with compassion and mirth!*

Len's "Funny side of cancer" resonates with the Plymouth Club's interpretation of Doctors' Sayings. I'm on hormone therapy for Prostate Cancer. My Oncologist might say to me:

*"For your prostate let's try Zoladex;
It's hormonal, confusing one's sex;
The fire down below
Will become a mere glow
But you'll grow Dolly Partonesque
pecs!"... too true!*

Laughter is positively therapeutic. Those of us who frequent Italian restaurants will know that the Dessert Menu will offer a number of Gelati. Gelato (singular) is a type of whipped ice-cream often flavoured with fruit and nuts and liberally doused with Amoretto or some such luscious liqueur. Gelatology is not, sadly,



the study of Italian ice cream but the ongoing study of the therapeutic value of laughter. Laughter releases

A Walk beside the Stream

It was a perfect day, as I walked slowly along the footpath, the sun directly overhead, its warming rays shining like spotlights through the foliage of the overhanging trees. The sunspots reflected a million times on the ripples of the gently flowing stream, moving away from me as it curved away into the distance.

Wild flowers were growing along the banks, and in the hedgerow to my left, on the other side of which I could see the perfect apple trees in an orchard, its fruit so colourful in red and yellow. This was such a perfect place I thought, and in wonder I could smell the flowers, which I knew to be impossible, as I had lost my sense of smell years ago. Heidi, my son's dog, which I was taking for a walk, spotted a moorhen in the stream, and went to jump in in order to chase it, I called quickly for her to stop, which she did, but realised that the words had emerged from my mouth before I had put my thumb to my throat for me to be able to utter the words. Without vocal cords, and breathing through a hole in the neck, that is really the only way that I could talk, but the words had emerged so easily. I knew that some people who had lost vocal cords could speak by controlling air through the stomach, but it takes years of practice. I put the lead on Heidi, as she was still keen to show me her swimming skills in the stream, against that dangerous moorhen.

I thought about dear Heidi, a much maligned beautiful lady Rottweiler, who loved her family dearly, and of all the times we had looked after her when my son and his family were away on holiday.

It was with a sudden shock, that I remembered she had died some eight years before of cancer, and this dog could not possibly be her. But it was and I was taking a ghost dog for a country walk. I stopped to try and fathom things out, and Heidi sat beside me licking my hand. I tried to think of when she first appeared to me on that day, but it had all started on

that footpath beside the stream. I forced myself to think of earlier in the day, and all I could think of was the vision of myself driving my car, when something very large came out from a side turning, and I knew it was going to hit me. It was a complete blank from that moment on until I was taking dear Heidi for a walk in those beautiful surroundings.

Nervously I felt at my throat for the white medical bib, but it wasn't there, and there was no breathing hole in my neck. I was stunned. I opened my mouth and said: "Heidi" looking down at her. It was my old voice! I felt inside my shirt for the bulge in my chest and the pacemaker had vanished as well. I seemed to be able to breathe easier, and my whole body felt different.

I realised what had happened earlier in that accident, I had not survived, and Heidi was leading me somewhere. It was with a very strange feeling that I continued along that path. We came to a very ornamental gate on the left, and we entered slowly, to see a man sitting apparently waiting for me. I said to him, "Is this heaven?" He smiled and said, "Yes, you are most welcome, we have been waiting for you." I asked about Heidi and he said, "No I'm sorry, we don't allow pets here." I explained that she had been dead for several years, and he replied, "Yes, I'm sorry, pets are in limbo outside."

I couldn't bear the thought of leaving Heidi a second time, so together we walked out of the gates, going goodness knows where. We suddenly came to another gate and we went in. A pleasant young man said: "I'm glad you made it, this is the real heaven." I said, "Why do you allow them to be there?" He said, "We find them useful in screening those who would discard their best friend."

Len A. Hynds

"Beer is proof God loves us and wants us to be happy." (Benjamin Franklin)

chemical endorphins in the brain which promote good health by reducing stress, increases oxygenation and circulation, aids one's immune system, encourages communication and, generally, improves one's quality of life. Alongside limericks, which contain the almost impossible challenge of keeping them clean! I love Spoonerisms. Wasn't it Dr Spooner himself

on the occasion of another Queen's Jubilee who stood up before the Dons and Undergraduates at a celebratory College dinner, lifted his glass for the loyal toast, and declaimed: "Gentlemen. Three cheers for the Queer Old Dean!"

Keep laughing, my dear fellow Larlys!

Clifford Hughes

Ask The Doctor

"Can radiation cause dizzy or fainting spells (vasovagal syncope)?"

Let's start by reviewing some anatomy. Then, I will address the problem some patients have when they turn their heads and get a little dizzy and light-headed. On either side of your neck are the carotid arteries which are the main suppliers of blood to the head and, more specifically, the brain. This artery comes into the neck from the chest as a single large artery, the common carotid artery, then splits in the upper neck to become the external carotid artery supplying blood to the face and head outside of the skull and the internal carotid artery supplying blood to the brain. Where this artery splits is called the carotid bulb and you can usually feel it as a pulsating mass in the upper neck. The carotid artery and especially the carotid bulb are enervated by some specialised nerve fibres that are sensitive to the chemical content of the blood and also to the pressure of the blood inside of them.

Now, let's say you have had surgery on the neck or radiation to neck. Remember that either of these can cause some degree of scarring around this blood vessel resulting in some degree of 'squeeze' on them. The nerves, that I mentioned above, read this as an increase in the pressure INSIDE of them and set in motion automatic measures to lower the blood pressure. These include a lowering of the heart rate and a dilatation of the blood vessels in the rest of the body. The net result of all of this is a relative lowering of the blood pressure to the brain and the sense of dizziness and being light-headed. This whole thing can be made even worse if you have some degree of atherosclerosis (cholesterol plaque) or if you are taking medicines for high blood pressure. Dehydration also may be a contributing factor.

If you have this problem, unfortunately there is not much that can be done to eliminate it. The most important thing is to simply be aware that the problem exists and not change positions rapidly, i.e. lying to sitting or sitting to standing. Take your time when you get up and don't immediately start walking.

You might want to make sure you are well hydrated and that your blood pressure is under good control and your anti-hypertensive medicine is right for you. If

On Our Side

My husband, John Langley-Mills, had a laryngectomy in December 2000 at quite a young age, we had two young girls at the time, our youngest just three years old. We did go to a few of the laryngectomee meetings held in Leicester and we were fortunate to meet a speaker from a voice valve company who arrived at the meeting as a speaker. She saw John's predicament, he had not been able to speak for two years and after some time we asked for her help. She gave us a contact – a wonderful lady at Charing Cross Hospital, Yvonne Edels, who specialises in the anatomy and physiology of laryngeal swallowing and voice production – altered form and function post laryngectomy, this lady helped John so much, and we always felt so lucky to have her on our side. John's throat cancer was completely cured with no re-occurrence.

We were also privileged to meet Bert Cullings and his wife before John was able to 'speak', Bert spent time talking to John about the way forward after a laryngectomy operation and was very positive and helpful. Some years later, however, John developed another type of cancer, this particular cancer led to his death in February this year and we have all felt distraught since losing John. I read the latest copy of *CLAN* and noted that one of your readers is having difficulty with supplies he needs, John was fortunate never to have had this problem. If I can be of any help to this gentleman – I have a lot of unopened supplies that I am sure will be of use to him would you pass on my email address to him.

Jennie Langley-Mills

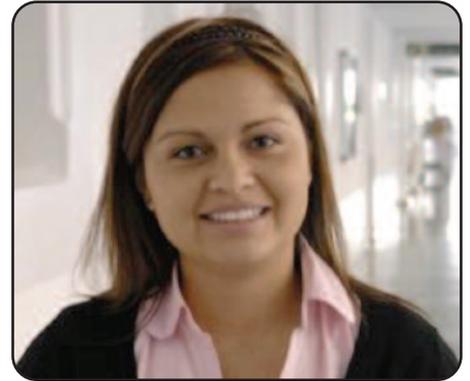
the problem is severe enough that you almost black out or if it occurs very frequently, please check with your doctor and make sure that you are not having transient ischemic attacks (mini strokes) or something wrong with the heart itself causing it to be an inefficient pump.

Glenn E. Peters M.D.

*Director, Division of Otolaryngology –
Head and Neck Surgery, University of
Alabama at Birmingham, Birmingham,
Alabama. From the IAL News.*

Building New Organs

In 2008, I was privileged to co-lead the team that provided the world's first stem cell based organ transplant to a woman from Colombia (Claudia Castillo: see picture). Her windpipe, damaged by tuberculosis, was replaced by a donor organ seeded with her own cells. Almost four years later, she is well and working full-time. In 2010, we were able to repeat the process for a 10-year old boy from Northern Ireland. Although he had a lot of problems for months afterwards, he is now at school, growing and very well.



These cases show us that it is technically possible to build new organs from stem cells. However, they remain isolated patients, as there remain a lot of hurdles to overcome. Ideally, we need to have organs that can be implanted 'off-the-shelf', but this requires a source of stem cells from another individual, with possible risks of rejection (as for conventional transplants); the scaffolds would need to be made from a synthetic material, but early experience with such scaffolds has not been wholly successful and better materials are needed; there are huge ethical, financial and regulatory hurdles that researchers have to negotiate to get such treatments into clinical trials. However, on the starting blocks are not just windpipes, but also hearts, lungs, kidneys and... larynxes!

As the number of donors for conventional organ transplants continues to fall, and the number of needy patients increases, this type of technology is sorely needed. Perhaps one day, though, we may indeed, and I hope we will, be able to produce a 'voice-box in a box'!

Martin Birchall

So I rang up BT. I said "I want to report a nuisance caller." He said "Not you again." (Tim Vine)

PC Gone Mad?

In the June issue of *Clan*, once again I read of someone with 'work problems' – getting work that is. I felt I must put pen to paper because I'm glad I had my larynx some 49 years ago aged just 18. I'm really mad at today's PC brigade – men in suits sitting behind desks saying what you can and cannot do just because you have lost your voice.

In my case, I worked for a local soft drinks manufacturer driving lorries and delivering heavy crates of 'pop'. All through my five ops and spells in hospital, my boss, who looked after his workforce, stood by me and my job was never in jeopardy. After five years, I decided to upgrade to driving HGVs and delivering beer for a local brewery. In those days, you delivered barrels and hogsheads manually – very heavy work. During this time I met and married my better half and we decided to enter the licensed trade as Club Stewards and then as Public House owners. I had no problems at all in my working life because we did not have the PC brigade we have today!

We both retired aged 60, some seven years ago and have been happily enjoying more time with our son and three daughters, three grandchildren and one great grand-daughter. Would I have had such a great life under today's rules? I don't think so. To use the old cliché: I could write a book!

PS I thought it was against the law to discriminate against those with disabilities.

Reg Dunton

Itzhak Brook Video Link

I would like to send you a link to the video of the Grand Rounds lecture I gave on 16 May 2012 for the Department of Surgery at Texas A&M in Temple Texas. I talked about my experiences as a patient with head and neck cancer, dealing with the medical and psychological aspects of life as a laryngectomee. The audio visuals are excellent.

The link to the presentation is:
www.youtube.com/watch?v=uYRkHZQy7_4

There's also my blog:
dribrook.blogspot.com

Itzhak Brook, MD MSC

A SELECTION OF REAL-LIFE LARYNGECTOMEE EXPERIENCES

These were taken from the internet

1. My doctor is at a teaching hospital and from time to time there's a resident with the doctor, and he does the check-up along with him and, without fail, he puts the tongue depressor in and says "Say ahhh!" (*Richard Boucher*)
2. My two-and-a-half-year-old granddaughter was a little frightened of me and my paraphernalia at first but she soon came around. She'll pick up the Servox, put it in her mouth (I use the oral adaptor) and begin jabbering. While she's holding the Servox in one hand, she has the other hand waving it back and forth. (I've always talked with my hands, even before surgery.) A few weeks after I came home from the hospital, she picked up a Kleenex and held it to her neck and faked a cough. She'll also get the tweezers and saline and say that she has to clean her neck! (*Patsy Armstrong*)
3. At work, some people can understand my Servox but many can't, so I write. A friend, Sandy, was visiting with me in my office and I was writing since she couldn't understand me and the Servox. Anyway, I'd just written my part of the conversation when she grabs the pencil and starts writing her part of the conversation. After a line or two, she stops and just bursts out laughing. I wrote, "I can hear." She said, "But, I want to write too." (*Patsy Armstrong*)
4. "When I came home after surgery and my great grandson saw me talking with the artificial larynx, he retrieved a block out of his toy box, stuck it against his neck and moved his mouth just like me." (*Al Weitzel*)
5. A laryngectomee using oesophageal speech was talking to a friend in a shop, when a bystander, hearing her voice, commented, "My, you're hoarse." She replied, "No, I've had my voice box removed and that's how I talk now." The bystander patted her sympathetically on the shoulder and said, "That's all right, honey, it'll grow back." (*Al Weitzel*)
6. On our final annual visit to my husband's Radiation Oncologist, three years after completion of radio-therapy, the doctor wanted to look down Will's throat. He first warmed the mirror so it would not fog up, then said, "Open wide and continue to breathe normally through your nose." It was very probably an automatic statement to him since before becoming a Radiation Oncologist, he'd been a dentist; but we both had a very good laugh after we left his office! (*Nancy and Will Crawford*)

GNR

Rowing Gold

Congratulations to rower Andrew Triggs Hodge, son of Liv Triggs Hodge, Sales Director of Kapitec Healthcare. The four winning rowers are: Pete Reed, Andrew Triggs Hodge, Alex Gregory and Tom James. (*Image taken from Olympic website.*)



News from the Clubs

Chiltern Chatterbox Club

At the club meeting on Tuesday 10 July Rosetta Hayes retired from the role of Secretary, a job that she has done tirelessly for over 25 years. The club had arranged for the meeting to be a social evening (unbeknown to Rosetta) and had organised a buffet and drinks supper.

Jim Hollier, whose late wife was a laryngectomee and has remained a constant supporter of the club, knows Rosetta and her husband Jim well, said a few words and reminisced over the years. The club then presented Rosetta with John Lewis vouchers, a bouquet of flowers and a card signed by everyone at the club. Jim, who has been a great support to Rosetta and the club, was presented with a bottle of wine and a card signed by everyone.

The evening was well attended by the members and their families and also by the speech therapists who have always been a great support to the club. Tony Hudson who is taking on the role of secretary remarked that: "Rosetta may be small in stature but he certainly had some big shoes to fill." Rosetta and Jim are not leaving the club and will continue to come along to the meetings as members. This leads us to ask the question – is Rosetta the longest serving officer of a laryngectomee club, it would be interesting to know!

The photograph shows Rosetta and Jim after the presentation.



The Windpipers, Blackpool

The Laryngectomy Conference at the Marriott Hotel, Preston was attended by 120 people from across the North West and was interesting and informative. The club had a number of trips: in July, a Lunch at the Boars Head, Ripley and Ripon and a River Cruise from Knutsford. Also in June the Cancer Laryngectomee Trust held a luncheon at the Savoy Hotel, Blackpool.

Happy Larrys

Just a quick update from the Happy Larrys club on our recent activities for inclusion in your next *CLAN* magazine.

We were lucky enough to be proposed by a member's relative as a charity to be supported by Halewood Transmission Plant Shopfloor Workers. As a result, Ann and Les Newland were invited to attend and received a cheque for £600.

We recently went for lunch at the Adelphi Hotel and 40 people attended. For the summer we have days out, meals and visits to the theatre in the pipeline, so watch this space!



Ian Newland

Cornwall Speak Easy

In June they met up with Plymouth Lary Club for a trip up the Tamar; followed by a cream tea kindly provided by PLC. On 4 July they had a brilliant visit back stage at the Hall for Cornwall. They saw the theatre from every direction – under, over, from the stage and the auditorium. They went all over the stage, which was set up for 'Ladies in Lavender', learned lots of tricks of the trade and heard several scandalous stories of stars past and present. The staff there couldn't have been more helpful and they will look at things differently when they next see a show there.

The second July outing was a joint meal with the Recovery Club at the Inn for All Seasons. Again, very enjoyable, with good food and excellent company. It was nice to see Jacqui and Emma as well as Di from the Clinic. The evening's quiz, which was very hard, was won by Di (Clinic) and Valerie (Speak Easy) team and Jean and Beryl (Recovery Club) – so they each get the cup for three months before handing it back for next year. A whip round of all the guests raised £100, which the Recovery Club generously shared with the Plymouth Club.

Then in August a meeting at the Victoria Inn, Threemilestone for lunch followed by a talk on the latest SLT equipment. In September there will be a meeting at Devoran for a soup lunch with the Plymouth and the Recovery Clubs.

Their *Newsletter* includes the following: *The Cancer Survivor's Bible* has just been published. This is the updated edition of *Cancer: The Complete Recovery Guide* (40% bigger!). Many people today are taking responsibility for their cancers and recovering. Ian Clements, an engineer who lives in Brighton (UK), is one whose

story can teach us a lot. Three years ago, Ian was in a hospice within days of dying of cancer. But a last throw of the dice got him out of the hospice and three years on he is alive and well and cancer free. His is one of over two dozen stories in the book (in pdf and Kindle versions). There is no doubt that there are many approaches that can help people live longer and in greater comfort – either they will help fight the cancer or they will help the body return to a state of wellness. That's why I wrote my book, *The Cancer Survivor's Bible*. At 550 pages this is the most detailed information resource available in print that looks at all sides of the world of cancer – conventional and non-conventional. Here are some testimonials I have received:

'This is an incredibly informative and useful book. Every one of you needs it in your library. This is, from now on, my primary encyclopaedia when I have a question about cancer and its treatment.' – Bill Henderson, author of *Cancer Free*. 'I recommend this book to everyone, whether or not you have cancer, as 'The' reference book on cancer. This book gives hope... It explains clearly the arguments for and against the multitude of treatments, both preventive and curative, and how to find them. I wish I had read this before I was diagnosed as doctors and the cancer charities didn't tell me any of this.' – D Bushell (Amazon UK)

The Cancer Survivor's Bible is available from all internet bookshops. You can find more information at: www.fightingcancer.com

While the official publishing date is 15 July, the book is available now. Don't wait. Please tell everyone you know about this important book.

Jonathan Chamberlain

News from the Clubs

Speakers' Corner, Shropshire & Mid-Wales

Their AGM was on 18 February and plans for the year were discussed. On 5 April Jeff Glover and Alan Morrison joined a large gathering to witness the handover of the initial stage of the Lingen Davis Cancer Centre. In June their Summer Trip was a return to Bridgemere Garden Centre including a meal. Then in July they had the first of their garden parties with Alan Morrison. In August Elsie Tong was the

host while the Summer Supper was to be at the Bridge Inn at Dorrington on 20 September. In addition they have held regular Pub Lunches including at The White Horse Inn in Shrewsbury (May), The Horseshoes, Pontesbury (July) and The Four Crosses (Bicton) in August.

The photos show various gatherings including their Christmas Lunch at the Lord Hotel attended by 22 members.



Two Drops

Two drops every four hours. My family doctor told me of an incident that actually happened to him back in the early days of his practice. He said a woman brought her baby to see him, and he determined right away that the baby had an earache. He wrote a prescription for eardrops. In the directions he wrote, "Put two drops in right ear every four hours" and he abbreviated "right" as an "R" with a circle around it.

Several days passed, and the woman returned with her baby, complaining that the baby still had an earache, and his little behind was getting really greasy with all those drops of oil. The doctor looked at the bottle of eardrops and sure enough, the pharmacist had typed the following instructions on the label: "Put two drops in R ear every four hours."

Plymouth Club

Plymouth

The May Monthly Club Meeting included a Talk by Roy Skates of the Devon Air Ambulance. An excellent presentation despite not being able to get the slide show working! The Club presented Roy with a cheque for the Trust from the Club and a card and a personal token of thanks. The Press-Don't-Panic audio alarm devices were issued out to those members in attendance. Cream Tea at the Strand Tea Rooms afterwards at about 1.45 – 2 p.m.

The June Club Meeting included a Trip up the River Tamar followed by a Cream Tea. 11 Club Members embarked from the famous Mayflower Steps at 12.15 p.m. and the boat sailed at 12.30, lasting over an hour. Members were asked to pay for the

river trip themselves but Club Funds paid for the Cream Teas afterwards. Tea was taken at the delightful Strand Tea Rooms afterwards at about 2 p.m. Members had a lovely day and the weather held off just long enough for them to complete the river trip. They were delighted to have Pat and Peter Clarke from the Cornwall Club attend.

Maggie (Derriford Clinical Nurse Specialist) and Julia (Derriford Speech and Language Therapist) also managed to find the time to attend the Cream Tea and they were so pleased to see them both!

The August Meeting included a Trip Across the Moors followed by a Cream Tea at the Cornwood Inn. Planned for September



was a Car Trip to Devon as guests of the Speak Easy Club, Cornwall. And a Talk by the Elm Veterinary Group, Plymouth. In October is their AGM and Laryngectomy Study Day 2012. The November Meeting includes a Talk by Mr Steve Peasse of Plymouth Police/Crimestoppers. And in December, Christmas Dinner possibly at the Novatel, Plymouth. In the evening there will be Carol Singing with the PLC Choir!

