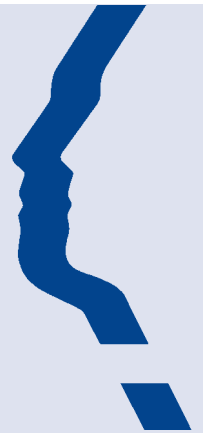


CLAN



THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS NEWSLETTER

Issue No. 146

September 2018

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A WORD FROM THE EDITOR

NO SOCKS PLEASE, WE'RE BRITISH!



It's been rather warm lately here in Godalming. So warm, in fact, that the Editor has started wearing sandals without socks! If it gets any hotter, he might even consider rolling up his trouser legs! But there is good news to report in that Macmillan have agreed to make one final grant to NALC for 2018. But from 2019, NALC will have to be self-supporting. So it's time to think of all the ways you and your club can fund-raise even more. And, of course, send us details and photos so that we can share the news. We'd love to hear from more of you. Otherwise we may soon have to re-title it "News from the Club"!

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. 147: 1 NOVEMBER 2018

NALC and MACMILLAN CANCER SUPPORT

Since its formation in 1975, NALC has had a close relationship with Macmillan and for many years was one of Macmillan's several associated charities. Macmillan funded all of NALC's activities and its staffing and premises costs. Some years ago Macmillan made a

decision to move away from providing funding via associated charities and in 2013 NALC was informed that its funding would be phased out. Macmillan gave assurances that it would assist NALC, in a variety of ways, to become financially independent.

Continued on p.2

To make a donation please complete and return this form to: NALC Suite 16, Tempo House, 15 Falcon Road, Battersea, London SW11 2PJ

I would like to make a one off payment and enclose a cheque payable to **NALC**.

I would like to make a one off payment of £ by card.

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

Name on card

□□□□	□□□□	□□□□	□□□□
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Start date Expiry date

Security code (3 digits on back of card)

If you would like to make a regular donation, please set up a standing order through your bank account to:

National Association of Laryngectomee Clubs

Sort Code: **20-46-60**

Account No: **03376745**

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

I understand that I must pay an amount of Income Tax/Capital Gains Tax at least equal to the amount.

NALC reclaim on my donation in the appropriate tax year.

Name

Address

.....

Tel. No.

Email

Signature

Notes from the President

HPV Vaccination

As you may have seen in the press, the campaign to extend the HPV vaccination programme to boys as well as girls has been successful. This is tremendous news given the large contribution of HPV to the increase in head and neck cancers. NALC, as a member of HPV Action, has been working for some years to achieve this. There is still work to be done to ensure parents take up the opportunity for their sons to have the jab and HPV Action may need to continue its advocacy for some time ahead.



Safety Campaign

Vice-President Tony Hudson has made excellent progress leading our campaign. He is working with South Central Ambulance Service and Community First Responders to raise awareness of the needs of laryngectomees in emergency situations. We are producing new information resources and if the project is a success we will extend it to the other emergency services and to other areas of the country.

Electrolarynx

A few months ago I contacted clubs seeking information about the provision of an electrolarynx to patients that need one. I am very grateful to all that responded to my request and the findings are provided elsewhere in this newsletter

Malcolm Babb

NALC and MACMILLAN CANCER SUPPORT

Continued from p.1

Starting from a very low base, NALC has grown its own fundraising activity year on year, and we expect that in 2018 we will cover 75% of our costs. A final grant from Macmillan will enable us to balance our income and expenditure.

Looking to the Future

From 2019 there will be no support from Macmillan; NALC has to raise all the funds needed to meet the costs of its work itself. In the past couple of years members of the laryngectomee community have responded marvellously to help NALC grow its funding streams. Looking in this edition of *CLAN*, and previous ones this year we have reported on some innovative ways laryngectomys and their families and friends have raised money to help us and we ask that they continue to do so. We need to grow our income to fill the gap left by Macmillan's withdrawal. If we cannot do that then we will not be able to continue all aspects of the work we do.

Thanks

We send our thanks to Macmillan for the support and advice they have provided during the process of NALC becoming financially independent from them.

We also thank everyone who has helped us by making a donation or organising or supporting a fundraising event.

Malcolm Babb

**MACMILLAN.
CANCER SUPPORT**

Ann Muir MBE

Ann was awarded her MBE in a ceremony on 3 July 2018 at the Palace of Holyroodhouse in Edinburgh. The MBE is given "For outstanding achievement or services to the community, long-term significant impact, and stands out as an example to others." They said at the ceremony it was for services to those with cancer in Scotland.



Ann Writes...

Recipients and guests have to arrive before 10am. All have to show ID and invitation before being allowed into the Palace grounds. We were ushered inside and those being given the award were separated from guests and taken into a large reception room where the Lord Chamberlain outlined the proceedings, and gave instructions on what we should do on meeting the Queen.

At 11am we were then led in smaller groups into the large reception room where the ceremony would take place, in front of all guests and where the Countess of Wessex's String Orchestra was playing. One by one we went to receive our award, stepping up to the dais, where we either curtsied or bowed to the Queen, who spoke to each person, congratulating and commenting on what we received the award for.

After all the awards, 64 in total, we were ushered out to meet up with our guests and could then stroll on the Palace grounds for a short time. After all the excitement it didn't seem possible that it was all over in just an hour!

Stoma Signs

Geoff Read added his name to a petition calling for stoma signs to be placed on disabled toilets and to add stoma-changing facilities within. He received the following response from the Government.

"Clean, safe and suitable environments for stoma patients are important. Approved Document M gives statutory guidance for new facilities, includes the needs of stoma patients and advises on the use of well recognised signage. Layouts for unisex accessible toilets already include coat hooks, a small shelf, a waste disposal bin and a wash hand basin."



Electrolarynx Provision for Laryngectomy Patients

Early in 2018, NALC received a communication from a hospital, which is a specialist head and neck centre, enquiring about the situation nationally for providing patients with an electrolarynx. In particular the funding for such devices was proving to be a problem. Subsequently NALC has sought to obtain an up to date picture of the situation, including a request for patients to share their experiences, with a letter sent to all our affiliated groups.

Since my surgery in 2002, the quality of speech obtained through surgical voice restoration (SVR) has improved significantly and use of the electrolarynx has diminished. However there will always be a group of patients that are not eligible for SVR because of the nature of their surgery, or who have later complications that make it non-viable.

A very effective electrolarynx can be purchased for less than £400 and can be expected to function effectively for around ten years. It is a much cheaper alternative than SVR. The NICE Guideline for head and neck cancer (NG36) estimated an average annual cost of £600 per patient for prosthesis management.

Several Problems

For patients who need to use an electrolarynx there are currently several problems. Some hospital trusts are struggling to find the money needed to provide an electrolarynx. Some patients are loaned a (secondhand) device, which does not function well and are given little guidance about its use. It is not the function of a support group to train a patient in setting up and using an electrolarynx, but I know this happens.

The responses received to the letter, along with additional evidence from visits to other trusts, provided a picture of the current situation. There was wide variation in how the provision of an electrolarynx was managed, in both how it was funded and who was given one.

- Responses were received from England, Wales and Scotland
- In total I had information for 11 hospital trusts
- Funding was an issue for five of them. Problems were eased in some of these by assistance from a support group, providing funds for the purchase of a device. Other national or local charities were mentioned as sources of grants to individual patients.
- Where the trust covered the cost of purchase, some mentioned the funds came from either the surgery or SLT budgets, but in most cases the source was not made clear.
- The majority of trusts only loaned a device to patients who had not had SVR. However a sizeable minority provided one for all patients, but those with a valve would return the device once they were competent with valve speech.

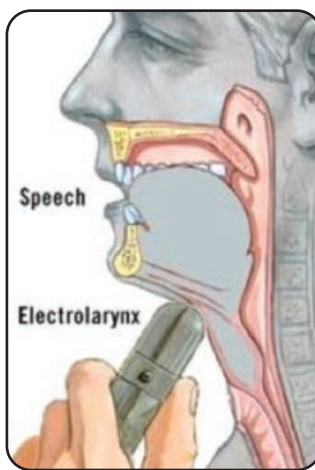
The NHS is facing significant challenges at the moment and shortages of both funds and specialist staff will have an impact on the matters discussed here. An electrolarynx is a relatively inexpensive item, especially when compared to the cost of valve maintenance. It is surely not unreasonable to expect that every laryngectomee ineligible for SVR is provided with one. As a next step I intend to make contact with commissioners and the professional organisations of relevant clinicians to seek their thoughts on this problem.

Malcolm Babb

New Cook Book

The sixth Head and Neck Cancer Awareness Week takes place from 17 - 21 September 2018. Last year, the MakeSense Campaign worked with Head and Neck Cancer survivors from across Europe to create a cookbook.

The book contains delicious recipes and also includes advice on overcoming personal challenges post-treatment. They will be launching the Cookbook European-wide for the Awareness Week in September 2018. Find out more at: makesensecampaign.eu/



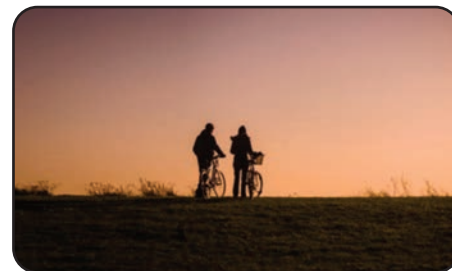
(Graz Institute of Technology)

Big Boys Cycle Ride 2018

We are a group of dads (Jez 'The Prop' Lawson, Terry 'The Butcher' Clarke, Andy 'The Coach' Hale, Ed 'The Chest' Lassman, Geoff 'The Chef' Ashworth, Paul 'The Entertainer' Edham, Alick 'Routemaster' Lawrence and Andy 'Big X' Cox), who for the last five years have raised funds for different charities during a three day cycle ride. It's the Big Boys Cycle Ride from 19 to 21 July but you can still donate to it. One of our original and ever-present members has recently been hospitalised for surgery and will be unable to participate this year. Choosing NALC was an easy decision for this year's ride.

Donating through JustGiving is simple, fast and totally secure. Your details are safe with JustGiving – they'll never sell them on or send unwanted emails. Once you donate, they'll send your money directly to the charity. So it's the most efficient way to donate – saving time and cutting costs for the charity.

You can access JustGiving at: www.justgiving.com/fundraising/andycox2018



Goodbye Ron

Ron Greenwood, whose family has previously shared many helpful suggestions, poems and tips with our readers over the last 10 years, has recently passed away at 92 years of age. NALC was one of the charities chosen for those wishing to make donations in his memory and was generously supported.



Cancer-Sniffing Dogs

Dogs can be trained to be cancer-sniffing wizards, using their sensitive noses to detect cancerous fumes wafting from diseased cells. This sniffing is non-invasive and could help diagnose countless people, which begs the question: If these pups are so olfactory astute, why aren't they screening people for cancer right now?

Here's the short answer: Dogs do well in engaging situations, such as helping law enforcement track scents or guiding search-and-rescue teams in disaster areas.

But sniffing thousands of samples in which only a handful may be cancerous is challenging work with little positive reinforcement. Moreover, it takes time and energy to train these pups, who, despite extensive preparation, still might miss a diagnosis if they're having a bad day, experts told *Live Science*.

But that's not to say that dogs can't be helpful in the development of man-made screening tools that 'smell' cancer. It's known that cancerous cells emit unique odours, but scientists have yet to identify the specific compounds responsible for these scents. One way dogs might be able to help pinpoint cancer-specific odours is to give the dogs certain cancerous samples to sniff, and then slowly remove compounds from the sample. If the dog stops responding to the sample after several components are removed, "then you know you've taken out that component of the mixture that is specific to the cancer," said Dr Hilary Brodie, a professor in the Department of Otolaryngology at the University of California, Davis.

Researchers could then analyse these individual components and develop biochemical tests that could reliably screen patients, he said. "There's lots that the dogs can do, but I don't think wholesale screening of the population is where it's heading," Brodie told *Live Science*.

Sharp Smell

In 1989, the British journal *The Lancet* published the first dog-sniffing-out-cancer report.

In a letter to the editor, two dermatologists described how a dog reportedly spent several minutes each day sniffing a coloured lesion on its owner's thigh, and even tried to bite off the spot when she wore shorts. Concerned, the woman had doctors inspect the lesion, which turned out to be a malignant melanoma.

"This dog may have saved her owner's life by prompting her to seek treatment when the lesion was still at a thin and curable stage," the doctors wrote in the letter. Other reports of dogs detecting malignant melanomas followed, but it wasn't until 2006 that high-quality, double-blinded studies were published, said Dr Klaus Hackner, a pulmonary physician at Krems University Hospital, in Austria. (In the double-blinded studies, neither the dogs nor their handlers knew which samples were cancerous.)

Soon, there were countless studies showing that trained dogs could detect specific cancers by sniffing biological samples, such as a person's breath or urine. That's because cells, even cancerous ones, give off volatile organic compounds (VOCs). Each type of cancer likely has a distinct VOC, meaning it has a different odour compared with other cells, Hackner said.

Given that dogs have more than 220 million smell receptors in their noses, they're excellent animals for sniffing out disease, Hackner said. In comparison, humans have a 'mere' 5 million smell receptors in their noses, he said.

Doggie Difficulties

Most dogs can be trained to recognise the odour of a specific cancer in about six months, Hackner said.

However, many studies had setups that work in laboratories, but not

the real world: often, the dog would be given five samples that always had one cancerous specimen. In reality, depending on the type of cancer, a sniffer dog might find just four cancerous specimens out of a batch of 1,000, he said.

If neither the dog nor the handler knows which four out of those 1,000 samples are cancerous, the handler can't give the dog positive reinforcement when the dog picks the right specimen, Hackner said. "I think this was one main point for why our study failed," he said. His 2016 work, which had a real-world-like setup, was published in the *Journal of Breath Research*. "We were not able to provide positive feedback because neither one knew in the screening situation if the dog was right or not. This was stressful for both the dogs and the handlers."

This situation could be remedied if there was always a planted cancerous sample in each set, so the dog could get a reward and wouldn't be bored after sniffing thousands of noncancerous samples from patients, he said.

Moving Forward

But even if the setup could be changed to accommodate the dogs, it wouldn't be a realistic way to screen patients, Brodie said. It would take an immense amount of resources to train dogs to recognise the many types of cancer that can affect humans.

In addition, while no test is perfect, at least doctors know how accurate different tests, such as mammograms, are, and at what rate they produce false positives and false negatives. But these rates would vary for each dog, Brodie said. Moreover, dogs can get bored, hungry and "have bad days, just like you and I," Brodie said. "You'd have to be carefully monitoring their effectiveness throughout their cycles."

Rather, Brodie and Hackner envision dogs helping researchers create and refine biochemical "nose" machines, known as e-noses, that could "sniff" patients and deliver diagnoses, they said. These machines already exist for certain medical conditions but could be made more sensitive and applicable to more diseases with the help of dogs, Brodie said. But the research isn't there yet, he noted.

In one project, Brodie and his colleagues were studying whether dogs could detect volatile organic compounds from head and neck cancer patients by smelling the breath patients had exhaled into a container. But the researchers put the project on hold after the dog trainer began broadcasting that her dogs could sniff out cancer.

"We didn't want to be affiliated with that," Brodie said. "We wanted to prove that they're detecting it, not state that they're detecting it and then prove it. You've got to do the science first. This is not even close to or near prime time."



Fido has a powerful nose © Shutterstock

*Laura GEGGEL, Senior Writer for Live Science
22 December 2017 and included in
The Voice Newsletter, Plymouth RHNCSCG*

Ask the Dentist: How Radiotherapy can affect Saliva

This article was published by The Irish News on 1 June 2018

Lucy Stock, dentist at Gentle Dental Care, Belfast, says cancer patients need to be aware of how treatments might affect their saliva. Always visit your dentist before cancer treatments.

Dry mouth, termed xerostomia, is common after radiotherapy... it is extremely uncomfortable, making speaking and swallowing difficult.

We normally give little thought to our spit, but we definitely notice when it's not there. Every day in the UK, 31 people are diagnosed with a Head & Neck Cancer (HNC). With increasing numbers of people undergoing radiotherapy for HNC there are more people living with the side-effects of not having enough saliva. Dry mouth, termed xerostomia, is common after radiotherapy. It's not only extremely uncomfortable, it makes speaking and swallowing more difficult and alters how things taste. Food can taste saltier, metallic; you can lose your sense of taste totally; and perhaps even worse, foods can taste foul, like sour milk.

Not being able to chew and swallow easily can reduce how much you eat and how well you eat, leading to weight loss and poor nourishment. Saliva performs numerous jobs. It starts digestion by breaking down food and flushes food particles from between the teeth. Crucially, saliva contains minerals such as calcium and phosphate that keep teeth strong. So, no saliva means that teeth decay rapidly and extensively. Even voice quality can change. Without enough saliva, bacteria and other organisms in the mouth take the opportunity to grow uncontrollably. Nasty sores and mouth infections, including yeast thrush infections, are run-of-the-mill. Luckily a dry mouth is usually a temporary nuisance that clears up in

about two to eight weeks, but it can take six months or longer for the salivary glands to start producing saliva again after radiotherapy ends.

Pilocarpine

In a 2017 study, out of several treatments tested, the drug pilocarpine gave the most significant improvement in dry mouth following radiotherapy. However, you may experience a side effect, albeit short lived, from this medication and it can take a couple of months to work. Artificial saliva's are available as lozenges, sprays and gels, the downside being that their benefits last only a few hours. The Biotene range is specially designed to help relieve dry mouths and includes toothpastes, mouthwashes and gels to give comfort and protect the teeth. You can buy small atomiser spray bottles from most chemists and fill them with water or fluoride mouthwash. If you cannot swallow, your nurse or doctor can give you a nebuliser to moisten your mouth and throat. Always visit your dentist before cancer treatments to maximise the health of your mouth. Relieve a dry mouth by:

- Sipping water often
- Avoiding drinks with caffeine which dry out the mouth
- Chewing sugar free gum
- Avoiding spicy or salty foods, which may cause pain
- Avoiding tobacco or alcohol
- Using a humidifier at night.

Published in The Voice



Oesophageal Voice Training Course for Speech and Language Therapists

11 October 2018, Nottingham

Do you wish to use oesophageal voice?

Are you already able to make some voice, but not sure what to do next?

Is your speech and language therapist looking for training to build skills to teach oesophageal voice?

Oesophageal voice is one option for effective communication after laryngectomy surgery.

However, there has been little professional training to skill Speech and Language Therapists to teach oesophageal voice in the UK in recent years, which rules out this option for many laryngectomees.

SVS Training Ltd is delighted to provide a skills-based course *Teaching Oesophageal Voice* for Speech and Language Therapists on 11 October in Nottingham.

The main course tutor is Miss Eryl Evans who received her training at the Mayo Clinic, USA, and became part of the Charing Cross teaching faculty for courses for laryngectomees and their clinicians.

She is the co-author of *Working with Laryngectomees* and until retirement provided a specialist Speech and Language Therapy at the Singleton Hospital. She continues to train speech and language therapists in the art and science of teaching oesophageal voice.

If you think that this course may be of interest to your local Speech and Language Therapist, please do pass on the details.

**Contact: www.svsassociates.co.uk
jackie.ellis4@btopenworld.com**

**ELEVEN PLUS TWO:
When you rearrange the letters:
TWELVE PLUS ONE**

**THE MORSE CODE:
When you rearrange the letters:
HERE COME DOTS**



Head and Neck Conference - November 2018

Chris Curtis became involved with The Swallows group, based in Blackpool, some years ago. In 2016 he organised his first patient conference in Liverpool. It has now become a two-day event, with one day for professionals and another for patients and carers.

This year, the event is taking place in Nottingham, in November. There is an impressive list of speakers and it provides a great opportunity for head and neck patients in the North Midlands and further afield to both share their views and hear of the experiences of others.

More details can be found at: www.yourcancerjourney.org.uk/conference

Highly recommended!

The Laryngectomy Guide

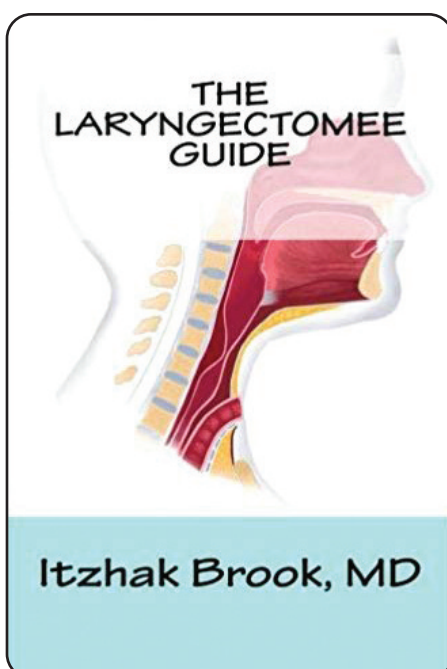
The Laryngectomy Guide is very helpful for laryngectomees, their caregivers and medical professionals. It contains information about the side effects of radiation and chemotherapy; methods of speaking; airway, stoma, and voice prosthesis care; eating and swallowing; medical, dental and psychological concerns; respiration; anesthesia; and travelling.

The Guide is available now in eight languages (English, Italian, Bulgarian, Turkish, Arabic, Chinese, Portuguese and Russian) and is being translated into more languages (Spanish, Iranian, Romanian and Serbian) by medical professionals in the corresponding countries.

The American Academy of Otolaryngology – Head and Neck Surgery and other otolaryngological societies across the world have made the Guide available for free download on their websites. Paperback copies are also given to laryngectomees in Taiwan and Bulgaria thanks to generous grants.

Links to obtain *The Guide* are below. The eBooks versions are FREE.

English: goo.gl/z8RxEt for paperback, and www.entnet.org/content/laryngectomee-guide for eBook. An Expanded Edition of *The Laryngectomee Guide* has recently



been published in English. It is twice the size of the original guide and contains new and updated information. The eBook version is available FREE at goo.gl/gecLgq and the paperback and Kindle editions can be obtained at: www.amazon.com/dp/1976852390

I hope to make the guide available for laryngectomees throughout the world.

Itzhak Brook MD, Professor of Pediatrics, Georgetown University Medical Center, Washington DC

Member of the board of Directors of The Head and Neck Cancer Alliance

Marathon Man

George Inglis, a member of the Glasgow Laryngectomy Club has just completed his 78th Marathon at the age of 78!

The oldest competitor, he finished in a very impressive 5 hours and 52 minutes.

Congratulations to George and thank you for the donation.



Donations

Thank you to all the clubs and individuals who continue to support us with their fund raising and donations. We are relying more than ever on the generosity and support of our members to help NALC survive.

We are extremely grateful to the patients and staff of Ward 29 Royal Victoria Hospital Belfast, which the late Alex McGuiggan had a very close relationship with, for their continuing financial support.

Don't forget as well as being able to make a donation on our webpage (www.laryngectomy.org.uk) you can also help by signing up to Give As You Live and Amazon Smile. Every time you shop on line NALC will receive a donation and it won't cost you a penny more!

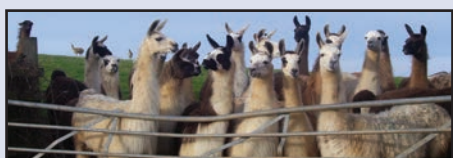
www.smile.amazon.co.uk

www.giveasyoulive.com

News from the Clubs

Speak Easy Club, Cornwall

In July, they held a Mini Fete in the gardens of the ENT waiting rooms at Treliske. It raised £225 to purchase a new machine for the ENT department. In August they had a meeting of those who have had their laryngectomies in the past year. They had an opportunity to learn more about the Club. They also looked at llama trekking on Bodmin Moor in September if they had enough interest. They have a joint meeting with the Recovery Group at the Cove at Treliske on 9 October.



Chesterfield Club

The highlight of a busy summer programme was a second trip to the National Memorial Arboretum at Alrewas. Since our first visit, many new memorials have been built so there was plenty to fill the day. Our enjoyment was enhanced by the brilliant weather and the plentiful sights of nature with terns flying over the River Tame, nesting coots and grebes, and the Poppy Field in full bloom.

As well as visiting several new patients we have been busy planning for European Head and Neck Cancer Awareness Week, 17-21 September, when we are organising a coffee morning. After some consideration we have finally ventured onto social media and have a twitter account: @hncHELP.

Plymouth HNC

The club has been as busy as ever (and their newsletter is a mine of useful information – well done, Geoff).

The Plymouth Support Groups Network met at the Moments Café during the summer and report that enthusiasm for the project continues to grow!

Two club members, Jean and Geoff Read, attended the Patients' Round Table on Access to Medicine also in June and met with attendees from as far away as Scotland and Portugal. It was a superb opportunity to exchange ideas.

In July there was a talk by Anne Marie Watts, a Veterans' Career Support Co-ordinator, at The Mustard Tree.

Daley Challenge

Recently one of our members saw on a social media website an item which intrigued him. Daley Thompson, well-known Olympian we all remember, was asking for anyone who wanted a challenge to join him on a walk up Mount Snowden. This was to mark his 60th birthday so he wanted people of 60 plus who also wanted a challenge. One of our club, Alan Wells, immediately applied, spoke to Daley explained why he wanted to join in. He just wanted to prove to others that there is life after laryngectomy and that it is good to challenge yourself.



So in June, Alan was one of the group setting off to walk to the top of Mount Snowden! It took him five hours, with lots of stops, but he made it. They were told that it was harder than the climb to the first base camp on Everest! Of course they had a good support team with them, lots of interviews and publicity – for laryngectomees and for over-60 challenges. Alan made it down again in three hours – to the

most welcome pint of beer in years! Our whole Club is so proud of his achievement that we want you all to share it.

*Val Seddon,
New Speakers Club, Stevenage*

