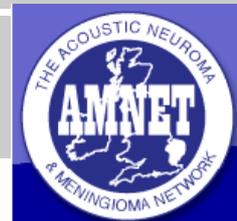


# AMNET NEWS



Issue 64 Spring 2016



**AMNET has a special birthday in June! The 20<sup>th</sup> Anniversary of AMNET Meeting is coming to you soon** - See below for details. Come along and celebrate with us at this event. We hope we have included something for all on this momentous day for our charity. AMNET members will have an invitation to this event included as an insert with this edition of the Newsletter. Please make sure you send your reply, so we are able to arrange catering details. This meeting will not be at our usual venue, so make sure you check the location before setting off – it is not far from Addenbrooke's Hospital, Cambridge, and is in the grounds of a well-respected garden centre.



The meeting on 11<sup>th</sup> June will also feature the AMNET Annual General Meeting which will start at 12.00 and be followed by lunch.

The AGENDA is included as an insert with this edition of the Newsletter. Please bring it with you to the meeting so that you have details of the accounts when discussed. If you are not going to be present, please return your proxy vote to Alison Frank.

**Report of our Autumn/Christmas Meeting from 21st November, 2015 which includes a presentation by Joy Badcock, Lipreading Teacher from Addenbrooke's Hospital, Cambridge.**



Our Chairman, Heidi Pratchett (right) welcomes AMNET members and introduces Joy Badcock to the Christmas Meeting

We began our Christmas Meeting with a shared buffet lunch and delicious Christmas Punch. Many thanks to everyone who contributed food, but mostly thank you to everyone who attended this meeting. The social aspect of our meetings is a wonderful chance for members to meet other people who share the experience of a skull-based tumour, and provides an opportunity for support and to exchange the shared experiences of coping with symptoms.

**Next Meeting is the 20th Anniversary Meeting** and will be held in the **David Rayner Building** which is located within **Scotsdales Garden Centre**, 120 Cambridge Road, Great Shelford, Cambridge CB22 5JT.

Doors will be open from 10.30 - 16.00. This meeting will also feature our **AGM** which will be at 12.00 and will be followed by a complimentary lunch.

**Presentation by Joy Badcock, Lipreading Teacher** (Continued from page 1).

We were delighted to welcome Joy Badcock to our Autumn/Christmas Meeting in November 2015. I have been attending Joy's lipreading class at Addenbrooke's Hospital for over a year now, and knew that members would find her to be both entertaining and a very informative speaker. She joined us beforehand for our shared Christmas lunch, which gave her a chance to speak to members and find out more about single-sided deafness and the specific challenges we encounter. Although I took notes when Joy presented her talk, she has very kindly shared the content of her talk which follows, which I hope will be helpful – especially to those who were unable to attend this meeting.



**Joy Badcock**

“Thank you for inviting me to speak today. I will endeavour to explain my work as a lipreading tutor/teacher (please note all one word – no hyphens or separate words for **lipreading**. In the US it is called “speech reading”).

You may be wondering how I came into this work ... Well, we all have a story, and mine started with sudden profound hearing loss when I was 16.

I had just started sixth form and found I couldn't hear my teachers. I was diagnosed with profound high frequency hearing loss and told there was nothing at all that would help me. However, later, selective digital hearing aids have helped a lot – with the development in technology more speech sounds and words are available to me. The cause of my hearing loss was “infection”? ototoxic antibiotics? I've never known, just got on!

I went to College and took a degree in Geography (perhaps a bad choice, with mostly bearded lecturers, lights out for showing slides – and no note takers in those days), but I enjoyed life ... hockey captain, which was a laugh as I couldn't hear the whis-

tle! (“Sink or swim!”). I bluffed my way into VSO and had a marvellous year in Freetown, Sierra Leone. I then came back to England and continued to teach Geography up to A-level for several years. This was hard, but I had developed a few coping strategies by then, including lipreading and the use of the overhead projector, which was invaluable.

Eventually, in my late 40's, I felt I needed to find something new and preferably, a challenge! I attended a brilliant course here in Cambridge for people seeking to change direction with their work, which gave me the confidence to apply for the Lipreading Teacher's Training Course (LTTC) at City Lit, in London. This was a year's training and my local mentor was Brenda Elcome. This was extremely hard work, with lots of study to understand different kinds of deafness, audiology and psychology, and much travel and meeting people = varied and enjoyable. I found the whole course fascinating, very relevant to me ... and challenging!

I have now been teaching Lipreading and Communication Tactics for 21 years in Cambridge, Bedfordshire and Northants, mostly in an adult education setting, where it was often a misunderstood subject. I was usually the only lipreading teacher and they never knew which department to put me in! I have therefore taught in departments for Special Needs, BSL (British Sign Language), and even Drama!!

***Memorably I was once included in a Modern Languages programme, but the worst of all was when lipreading became described as a “Leisure Pursuit” – which it certainly is not.***

That was the thin end of the wedge, as people had to pay, and nationally there were a lot of class closures. In May 2009 I retired, having found successors to teach all my classes. Then in September 2009 I found myself taking the two lipreading classes here at Addenbrooke's Hospital, and seven years later I am still here. Now that lipreading is recognised as “*useful*”, more people are training and classes are developing as the need arises.

Lipreading classes are planned with the aim of helping people to cope better with their hearing loss, and intended for a wide cross-section of people to join in. Mostly students are “hard of hearing”, and of all ages. My qualification enables me to teach lipreading to adults with “**acquired hearing loss**”. Lipreading students are not **usually** born deaf –

those people usually grow up using BSL. Amongst the students the *degree* of hearing loss varies enormously from profoundly deaf to having no loss at all (professionals, students' partners). People commonly have high frequency hearing loss, often age-related, and thus they struggle with clarity of speech, but there are many other causes and types of hearing loss. One or both ears may be affected, and hearing loss may have been gradually progressive or very sudden. Some students may have a Cochlear Implant, some have Tinnitus or Meniere's Disease. Sometimes English is their second language – so the challenges in teaching are varied.

However, people share a common target – *to improve their communication and develop more confidence* – to allow for as normal a social life as possible – so it's all positive!

We have a happy relaxed atmosphere of mutual support, just like you all here at AMNET.

### What actually happens in Lipreading and Communication Tactics Classes?

Classes are organised to give students the chance to *observe* and identify sounds we use in speech. We look at phonetics and how sounds are made – how air is manipulated by lip shapes, and also by the tongue, teeth, jaw and in the throat. A lot of work in the class is done *without voice*, so everyone is in the same position and they have to use their eyes to best effect, then things are voiced to clarify. It “takes a little longer to listen with your eyes”, but lipreading is complex, and sounds do *not* magically become intelligible words. This depends on other aspects of the conversation which we use to help us like:

- What is the *expression* on the speaker's face? How are they feeling? Are they asking a question?
- What does their *body language* suggest? (This is often associated with expression).
- What is their *tone of voice*? (Intonation). How are they *using language*?

NB students are encouraged to maximise what hearing they have, use their hearing aids or cross aids (it's a good place to start!), and to maintain them well. So far, I have only covered how we use **Eyes** + **Ears** to get the message, but we also need to use our **Brain**! Lipreading can be very demanding.

What do we *know* about the speaker – their family/work/interests/pets ....? *Where* are we having this conversation? *What* has just happened? All this leads to the most important thing of all .....



**CONTEXT.**  
What is the subject of the conversation? We must ask *what/where/who/why* are we

talking about? We need to learn to be assertive enough to ask people to help fill us in. This is essential to help us keep up and not become isolated.

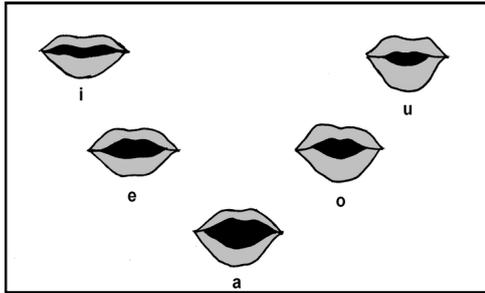
I can give two opinions about lipreading, that are apparently conflicting:

- **Lipreaders can hear better** – This is actually **atla's** unofficial “slogan” (**atla** is the Association of Teachers of Lipreading to Adults). I often have feedback from students along the lines of “... says I am much quicker off the mark these days”, “I've been going to a new group activity, and love it”, and “your new hearing aids are brilliant”. All this is very pleasing to witness.
- **“Lipreading needs the agility of an acrobat and the persistence of a leech”** – this was said by Jack Ashley and just about sums it up! He was almost 100% deafened as a result of surgery as a “young” MP of 45, and amazingly he managed to follow most of the speeches in Parliament by lipreading, until “**Palantype**” was invented, allowing him to read the words on screen. Hearing loss can be an isolating disability, of which Jack Ashley famously said “deafness separates humans from mankind”.

### What does a typical lipreading class include?

Lessons are 2 hours long and include a coffee/tea break. The social side of the class is very important and it is lovely to see students make new friends, especially if they have been isolated. Courses are designed to run for 30 weeks over 3 terms, and get progressively more difficult as the course continues. The year begins with a focus on easily visible consonants like p, b and m and moves on to the less visible ones like t, d and n.

The focus then shifts to the 20 vowel sounds. AEIOU sound very different in some words.



A typical lesson will focus on a *particular distinctive sound or group of sounds*, which will be prac-

tised by observing and learning. Having a good sense of humour is a real bonus as *sounds* in a group look alike and therefore *words* may look alike too, e.g. fan and van. Here a few humorous examples:

1. She sat in the bar with her double **chin** (should be double **gin**)
2. If you've finished with the **baby**, I'll throw it away (should be **paper**)
3. She always wore **vegetable** clothes (should be **fashionable** clothes)
4. I usually keep a **pills and booze** by my bed (should be **Mills and Boon**)

The more practise we have, the more we can solve these confusions and not substitute it for one that is usually nonsense. The more you practise and start to recognise what the word looks like then a sense of satisfaction is gained and social occasions can again become a pleasure.

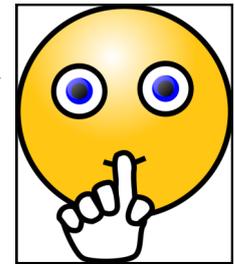
Lessons sometimes follow a topic, e.g. colours or numbers. These are of practical interest

– *knowing that 8, 9 and 10 look alike is very useful*. Try saying these numbers yourself and see what you think, especially if you look in a mirror.

Awareness of words that look alike means we can ask closed questions to clarify meaning.

Most lessons begin with a bit of theory to look at the phonetics and some short exercises to get the brain focussed. I tend to then present a piece of prose on a topical or unfamiliar subject without my voice.

This is a challenge to me to find something people might *want* to know about. We then move on to more varied activities to rest the eyes and allow lipreading of others in class, so we work in pairs or groups with games, quizzes and usually a joke. This gives plenty of practice with lipreading skills, and fun features too.



In addition, we look at **tactics for situations that can be difficult ...** and discuss strategies together. For example, at medical appointments, meetings, shopping, social events, restaurants etc.

– *planning really helps*.

We share ideas about the importance of choosing a venue with good acoustics (soft furnishings, if possible), lighting, uncrowded, and **specifically, where** we sit – it is good to have one's back to the wall, with light behind us and to be next to/facing the person we want to speak to.

These sessions are very lively and students learn from others' experiences, like the suggestion to *choose something from the menu that isn't crunchy!*

I invite **guest speakers** which include specialists on single-sided deafness, Cambridgeshire Hearing Help, Hearing Dogs, Hearing-aid Maintenance and share information about local groups/organisations like Cambridgeshire Hearing Help, STAGETEXT performances etc.

### Finding a Lipreading Class

We have been very fortunate here at Addenbrooke's as people have been able to continue in a class for as long as they want/need and every year about half of the 15 students leave, which makes space for those on the waiting list (accessed through Audiology). I am very concerned, however, that there are only my 2 classes in Cambridge itself now, but there are some in the Fens, plus an evening self-help group in Chesterton. There are several classes in Norfolk and Suffolk and a few in Hertfordshire and Essex. Ask your audiologist or consultant for details. I really would recommend trying a class in your area – you

have nothing to lose and maybe a lot to gain, particularly with confidence in coping better with communication. Your tutor will understand your difficulties and is experienced in planning courses that are relevant and fun (progress is always best when we are relaxed). The social side of classes is a bonus too. I only wish I had been able to join a class when I was younger and feeling a bit isolated, but there weren't any near me, until I started them up."

Joy was very keen to point out that lipreading classes can offer a lot of help and support, as well as fun and friendship, to just about all AMNET members. Lipreading students often have single-sided deafness, but not always due to vestibular schwannomas or the result of corrective surgery. It is invaluable to discover how others manage this change in their hearing experience and it is reassuring to know that tutors understand the difficulties that single-sided deafness can present.

Details of a local class for you can be found by looking at:

"**Learn to Lipread**" and "**mapsearch**" on the **atla** (The Association of Teachers of Lipreading to Adults) website:

<http://atlalipreading.org.uk/learn-to-lipread>

At this point Joy rearranged the seating and members present had a go at some lipreading exercises set in a restaurant with two different menus. A great time was had by all and much discussion was generated. Joy circulated around the room and was able to offer helpful guidance to specific problems that people were experiencing.

To finish the session Joy told us a joke and I thought I would include it here for your amusement.



A group of friends meet and go out for a meal every 10 years.

When they were *in their 40's* they went to a restaurant called ***Ocean View*** – as the waiters and waitresses there were gorgeous! Ten years later, *in their 50's* now, they decide to go to ***Ocean***

***View*** again – the food was good and the wine recommended. Ten years later (*in their 60's*) they chose ***Ocean View*** again – it was so relaxing by the sea! Another ten years on, *in their 70's now*, they chose ***Ocean View*** – it had installed a lift! When they were *in their 80's* they thought they would try somewhere new – ***Ocean View*** – because they'd never been there before!

### **Plea in Parliament for Provision of Lipreading Classes**

On the **Action on Hearing Loss** website I noticed that on 27<sup>th</sup> January 2016, Molly Berry, an **atla** Lipreading Tutor, like Joy Badcock, gave a presentation on the need for more lipreading classes to an All Party Parliamentary Group on Deafness in the Palace of Westminster. Molly is profoundly deaf and has a cochlear implant, but spoke out by saying:

**"I am here to ask for help in providing lipreading and managing hearing loss classes to all who need them".**

She pointed out that there are 10 million people with hearing loss in this country, but that only 100,000 of that number were born deaf. She added that when she mentions lipreading classes to people they immediately think of sign language (BSL). Audiologists are encouraged to discuss lipreading classes with patients during their consultations. This is where I discovered the possibility of attending a class, and this was my point of access to a place on a waiting list at Addenbrooke's Hospital. Molly Berry suggested that in some areas where classes are not provided free of charge, that it might be possible for GP's to prescribe a course of classes, in the same way that they can prescribe a place on a weight loss programme or help with smoking cessation.

She feels it important to inform students about communication support, as there is no point in having lipspeakers, speech to text therapists (STTR) and note takers, if the majority of people that could benefit from them don't know they exist, and she firmly believes that most people don't know about this.

It will be very interesting to see if anything comes about as a result of her presentation.

**News from Action on Hearing Loss  
(formerly RNID)**

In June 2015, **Action on Hearing Loss** (formerly RNID) launched a campaign called “*Subtitle it*” and as a result of this, over 3000 members got in touch with



Ed Vaizey, Minister of State for Culture and Digital Economy, asking him to take action to stop the digital exclusion of people with sensory loss.

Lilian Greenwood MP brought forward a Private Members’ Bill in support of the campaign and 70 MPs signed up to back the AOHL call for legislation on subtitles, signing and audio description on video-on-demand TV.

I find subtitles on BBC1 and BBC2 on my TV to be quite readable, but ITV and Channel 4 less so. For those of you who access SKY, Virgin and other digital providers, (however you view transmissions), this new legislation could well make your viewing experience more enjoyable.



The charity has been working with the **County Council Mobile Library Service** and this year will extend their services in **providing hearing aid batteries** to people that live in many more villages than Cambridgeshire Hearing Help currently visit. The Mobile Library Service covers the whole county and has 4 vans that will make their usual short stops in villages around Cambridgeshire. The vans will have a small stock of batteries and the driver will have a flow chart of questions to ask, plus leaflets to direct people to Cambridgeshire Hearing Help sessions, if help is needed with re-tubing.

**Have you had any problems with Hearing Aid Batteries Recently?**

The following article appeared in the February 2016 Newsletter issued by **Cambridgeshire Hearing Help**. (*Thank you, Frances Dewhurt for your kind permission to reprint this information*). \*See below for a message that Frances has since been asked (by Addenbrooke’s Hospital) to circulate at hearing help sessions.

“Addenbrooke’s have been distributing mercury free batteries. While this is great for the environment it is causing a few issues, predominantly with Phonak aids and especially when using FM systems (with ear level receivers) and wireless streaming. Some users are reporting very short battery life, intermittency, false battery warning alerts and spontaneous restarts.

Investigations have shown that the problem is with the Zenipower batteries rather than the hearing aid. Addenbrookes are recommending that users remove the sticker at least 2 minutes (preferably 5 minutes) before using. There is evidence that mercury free batteries take longer to activate (air needs to get into the battery when the sticker is removed) and the battery life can be 10% shorter than a mercury containing battery so this is now even more important.

**ALERT !**

**Addenbrookes hospital have advised that some ZeniPower mercury free batteries have a small risk of explosion.**

**If you have any ZeniPower batteries please check the “Best Before Date”.**

**Do not use any ZeniPower batteries from packs with a “Best Before Date” of 08-2018 or 09-2018**

**If in doubt do not use ZeniPower batteries. Check with your battery provider to ensure your batteries are safe to use.**

**Cambridgeshire Hearing Help CIO Charity Reg 1154071**

**Cambridgeshire Hearing Help** will be present at the **20<sup>th</sup> Anniversary Meeting** on Saturday 11<sup>th</sup> June, 2016, with an exhibition of equipment, which will be manned by a representative who will be able to answer questions that you may have about your hearing experiences, or about aids to living that might make your hearing experience more enjoyable and safe. This is a valuable opportunity for you to find out what equipment is available, how it might be relevant to you, and will be demonstrated by people who understand the experience of living with a hearing loss.

We were due to hear from Frances Dewhurst at our November 2015 meeting, but unfortunately she was unable to attend due to a family illness. We omitted to mention this at the start of our Christmas Meeting, and on behalf of the AMNET Committee, please accept our apologies for not keeping you informed.



Dr David Baguley with his award

Dr David Baguley, Director of Audiology at Addenbrooke's Hospital, has been awarded the "Outstanding Services to Audiology" award, the "**Golden Lobe**", by a national organisation. David Baguley received this award at the Ninth Association of Independent Hearing Healthcare Professionals (AIHHP) in November 2015.

On receiving his award he very graciously com-

mented: "I am delighted to have been given this prestigious award. I have outstanding colleagues at Cambridge University Hospitals and I thank them for their support".

This picture of David Baguley was copied from the Addenbrooke's **News and Events** page on their website. I thought readers would be pleased to congratulate Dr Baguley and his team for the outstanding services we receive from them as a group of patients, and to do so by relaying this news here to AMNET members.

## Research Articles

### **Toxic secretions from intracranial tumor damage the inner ear** (Public Release: 22-12-2015)

Many thanks to Peter Otley for flagging up this article, which he noticed on the internet and for forwarding it on to me, so that we can share the information with those of you who may be interested in following up this reference. Peter found this article on: *EurekAlert! AAAS: The Global Source for Science News*

Dr K M Stankovic, M.D, Ph.D, FACS, Otological Surgeon and researcher at Massachusetts Eye and Ear, (a Harvard Medical School teaching hospital in the USA), looked into why some vestibular schwannomas cause hearing loss even though they are not large enough to compress nearby structures that control hearing, and why it may be that some large tumors do not cause hearing loss, yet some small ones do.

The research team (see details of others at the end of this article) identified a compound called TNF $\alpha$ , which is a toxic molecule secreted from human vestibular schwannomas. This compound has been implicated as a factor in other forms of hearing loss. In their clinical study, the team found that the application of human TNF $\alpha$  to the cochlea of a mouse caused cellular damage which correlated to hearing loss in humans. The authors in this research study are hopeful that in future new therapies may be developed, because there are known ways to inhibit the body's production of TNF $\alpha$ .

Other authors of the paper include Sonam Dilwali of Mass. Eye and Ear and the Program in Health, Science and Technology at Harvard and MIT; Lukas Landegger of Mass. Eye and Ear, Harvard Medical School and the Medical University of Vienna; Vitor Soares of Mass. Eye and Ear, Harvard Medical School and the University of Brasilia; Daniel Deschler and Konstantina Stankovic of Mass. Eye and Ear and Harvard Medical School.

(Permission kindly granted by Suzanne Day, Media Contact at Massachusetts Eye and Ear to reprint the information detailed above).

**The impact of SSD on hearing ability and how to provide a holistic approach to rehabilitation.**

In a recent edition of *Audiology Matters*, edited by Mr Neil Donnelly, Consultant Otoneurological and Skull Base Surgeon, Cambridge University Hospitals, Cambridge (*ENT & audiology news* Vol 24 No 4 September/October 2015, p 71-94), leading specialists in single-sided deafness (SSD) were brought together from different fields to explore the impact of SSD on hearing ability and provide a holistic rehabilitative approach.

Please do have a look on-line at the series of articles which are included in this edition, many of which are by members of the Skull Base Team at Addenbrooke’s Hospital, Cambridge. The following articles are featured and may interest you:

- **Aetiology, investigation and acute management of sudden sensorineural hearing loss by Edwin Halliday (pp 72-74).**
- **Audiological and psychological consequences of single-sided deafness by Rachel Knappett (pp 77-78).**
- **Music and single-sided deafness: challenges and solutions by Gemma Crundwell and David M Baguley (pp 81-82).**
- **A patient’s perspective on single-sided deafness by Chris Mennan (pp 84-85).**
- **Rehabilitation of unilateral sensorineural hearing loss: bone vs air conduction by Thomas P C Martin (pp 86-87).**
- **Rehabilitation of single-sided deafness with cochlear implants by James R Ty-some (pp 89-90).**

There is so much information contained in these articles by the team at Addenbrooke’s Hospital and in other articles in this feature by their colleagues elsewhere. We are hoping to feature one of the team from Audiology, Addenbrooke’s Hospital, at our next AMNET Meeting in November 2016 – so

the content of that presentation will form the basis of the next Newsletter, and will hopefully feature information from the above articles. If this is not the case, and there is anything here that you would like me to pursue, as Editor, please contact me (see back page for contact details).

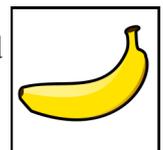
Our president, Alison Frank, holds the AMNET subscription of this publication and has it available at meetings, for those of you who would like to read/borrow an issue. Please approach Alison Frank for further details (see back page for contact details).

**Food for thought – some foods which can give your hearing a boost**

A member of the AMNET Committee handed me a publication entitled “**healthnews**” dated Jan-April 2016. This appears to be published by a branded hearing specialist, so I am unable to name the source because we are unable to endorse proprietary products. However, it contained some simple everyday advice about foods that may benefit our ears just as much as the rest of the body, so I will include this for your information.

Scientists in a Special Interest Group (SIG6) (Perspectives on Hearing and Hearing Disorders) in the American Speech-Language-Hearing Association (ASHA), noted although a balanced diet is always advisable, that several minerals, vitamins, antioxidants and nutrients could give your hearing a boost when included in your daily routine. *The role of nutrition in healthy hearing* was published by C Spankovich in November 2014, Vol 18: 27-34, and the following information from that source included in the “**healthnews**” publication:

**Foods rich in potassium** – including bananas, apricots, melons, oranges and potatoes, may benefit the way cells in the inner ear interact. As levels of these cells decrease with age, it is important to replace them.



**Leafy green vegetables** – green vegetables like spinach and broccoli are a good way of getting more folic acid into your diet. Folic acid has been



found to slow the development of age-related hearing loss.

**Citrus fruit, fresh herbs and strawberries** – all great sources of vitamins which act as antioxidants, can boost the body’s immune function and help resist ear infections.



**Almonds and sunflower seeds** – rich in vitamin E, are helpful in revitalising blood vessels and nerves around the ear.



**Meat and fish** – rich in vitamin D, strengthen bones, including the tiny bones in the ear. Vitamin D can be found in oily fish, eggs, fortified fat, spreads and breakfast cereals, as well as through exposure to sunlight.



**Vitamin B12** – a deficiency in vitamin B12 can result in hearing loss. A good source of this vitamin can be found in a variety of meats, salmon, cod, milk, cheese, eggs and some fortified breakfast cereals.



It should be noted that some people are advised to beware of some of the foods listed above if they are taking medications which could be influenced by eating them. If this is the case you are likely to have been told by your GP when a medication is prescribed that you should not eat certain foods.

Although the source of this information claims that these foods “*can*” give your hearing health a boost – something those of us with single-sided hearing loss may be keen to do, so we can make the most of the hearing we still have – it is always important to eat a balanced diet, and include the foods listed, but not to suddenly eat large quantities of any one food.

### Local Groups and their news

### Cambridgeshire Tinnitus Support Group

Another member of the AMNET Committee handed me an article which appeared in the **Cambridge**

**News** (February 8, 2016) p 19, which featured Alan Yeo, a tinnitus sufferer who helps run the **Cambridgeshire Tinnitus Support Group**. The article was entitled: “**Help is out there for tinnitus**”, and also featured Dr David Baguley, Director of Audiology at Addenbrooke’s Hospital. The team at Addenbrooke’s see about 800 patients a year with symptoms of tinnitus and Dr Baguley is quoted in the article as saying: “the priority over the next few years.... will be to turn tinnitus down and the sound even off”.

This group has just over 60 members and meets five times a year in the Meadows Centre, St Catharine’s Road, Cambridge, CB4 3XJ, on Saturday mornings between 10.30 and 12.30. The group is the Cambridge Branch of the **British Tinnitus Association**. They produce a newsletter prior to each of their meetings, which you may be interested in attending. Meetings for the rest of the year will occur on:

- **Saturday 18 June:** Preliminary results from internet-based intervention: “Conquering Tinnitus” by Eldre Beukes, PhD student, Anglia Ruskin University, Cambridge.
- **Saturday 17 September:** A taste of Taoist Tai Chi - Chris Tate and Pat Wells Johnson, Cambridgeshire Branch of the Taoist Tai Chi Society.
- **Saturday 19 November:** Self-Help session and Bring & Share Lunch (plus mince pies and mulled wine!) - Food wish list will be circulated prior to the meeting.

For more details, contact **Alan Yeo** at [mga978@hotmail.co.uk](mailto:mga978@hotmail.co.uk) or ring him on: 01223 243570.

### Cambridge Hard of Hearing Club

Have you heard about this club which might be very helpful for some members? Having attended a talk at the club this afternoon, (31st March, 2016), with another AMNET member, I have to say I was very impressed by the warm welcome we received.

The **Cambridge Hard of Hearing Club** welcomes all those experiencing hearing loss and meets once a

month on the last Thursday of the month. The meeting today was about the butterflies we might see in our gardens, and was given by one of the members.

The **Cambridge Hard of Hearing Club** meetings are held at the same venue as the Tinnitus Support Group, featured on the previous page, which is the Meadows Centre, St Catharine's Road, Cambridge CB4 3XJ. The meeting room is fitted with a hearing loop, and the absolute bonus to me was that a **speech to text** operator was present and relaying text onto a screen in real-time. Throughout the year the club organise speakers, but also have meetings where members can socialise and play board games.

Their next meeting, at the end of April, will be their AGM and to set their programme for the next year.

**Contact details:**

For those with computers the Club website is:

<http://groupspaces.com/CambsHoHClub/>

and their e-mail address is:

[Cambs.hohclub@yahoo.com](mailto:Cambs.hohclub@yahoo.com)

For those without access to websites: please text Chris on 07876 108963

or write to:

Mr David Pilkington, 48 Gough Way, Cambridge, CB3 9LN.

Does this sound a bit like you - it was written by the Club Publicity Committee Member?

When my hearing suddenly became much worse I only wanted to retire to the garden, read, or watch TV subtitles, but we all need to socialise. It was much easier to do this with people who shared and understood my problem. Do come and join us. Chris

**Editorial**

Hopefully there is something for all in this Newsletter. I remain truly grateful to you all for sending me interesting articles for inclusion here. As a self-help charity, that is really what we are all about.

Our 20<sup>th</sup> Anniversary celebratory meeting is an opportunity for you to come along and meet up with others members in the comfortable setting of the David Rayner Building at Scotsdales Garden Centre, in Cambridge. It doesn't seem long since we were meeting in The Clinical School at Addenbrooke's to celebrate 15 years. Please see the invitation enclosed with this Newsletter for further details ..... please make sure that you send your reply to Alison Frank.

This year has been one of change - Alison is now our Honorary President, Heidi Pratchett is our new Chairman and we have welcomed Stephanie Hazelwood and Henry Sessions to the Committee. Our Treasurer, Carol Clothier, will be standing down as Trustee at the AGM, but has kindly offered to continue helping with our book-keeping. Her husband, Mick, will also be stepping down as Secretary at the AGM. Carol and Mick have been valuable members of the Committee since 2012 and I am sure you will all join us in thanking them for their expertise and generosity in the time they have spent in their roles for AMNET.

As you will see from the Charity Notices on the page facing this, we will be continuing the change that has begun this year as we go into the 21<sup>st</sup> year of AMNET as a charity. We would like to welcome your input, whether as a member of the Committee, or as someone who might be prepared to take on a role in a remote manner, from the comfort of your home perhaps? We are very kindly supported by Carol Brunt, one of our members, who distributes the Newsletters. She collects the Newsletters from the printers and is sent a list of names and addresses for circulation. This sort of role does not involve Committee meetings and can be done at a time that suits you. Maybe you are website-savvy or would like to help in some other way.

Sally Hardy, Editor

## Important Charity Notices



### Amending the Constitution

As some of you will be aware the Trustees reviewed the AMNET constitution in 2014. The original constitution was drawn up in 1998 and we felt the time was right to simplify it and update it along the lines suggested by the Charity Commission. Parts of this needed to be approved by the Charity Commission whose wheels move very slowly. We had approval for most of the new constitution last year, but they did suggest an amendment to the section related to what we would do if we did need to wind up the charity for any reason.

The original clause said any money would go to a similar charity, but the Commission suggested we should broaden this, hence the proposal on the AGM agenda. We need this to be approved and officially recorded in the minutes of the AGM, in order to comply with the Charity Commission.

Please complete the Proxy form if you are unable to attend the AGM, to ensure we have enough voters in order to do this.

Chris Richards

### Updating the Webpage

Our website was designed over 10 years ago and is beginning to look dated. The Trustees have been addressing this problem and after some investigation into how the world of websites and social media have changed, have commissioned Paul Girling of Greystoke Graphics, who kindly set up and managed our first website for free, to work on an updated site which will be more responsive to the current on-line and social media world.

A small sub-committee of the Trustees is overseeing this and we hope that it will be on line very shortly. We are hoping that the new site will provide a service to members and also reach a wider audience to whom we can offer support and the

opportunity of membership. The site will need some ongoing management and monitoring. If you feel this is something you would like to be involved with, please let one of the trustees know.

Chris Richards, Stephanie Hazelwood and Carol Clothier

### Membership Renewals – E-mail address details

At a recent Committee Meeting we agreed that renewal letters sent out in June 2016, and the ones at the start of 2017, will include a space for you to include your e-mail contact details. If you do not have a computer or would prefer to be contacted in some other way, then please let us know if and how you would like to be contacted. As we have moved from 3 meetings a year to 2 meetings, we are hoping to be able to offer local group meetings in addition. We appreciate that quite a large proportion of our members joined AMNET before the year 2000, and that transport and mobility may well be an issue for you, and that the support that a small local group can offer might be quite welcome. Alison Frank already has contact with one small local group in North Norfolk.

We need to be wary of confidentiality issues in the storing of personal details like e-mail addresses and can categorically assure you that your details will not be shared with any other organisation. By careful management of these contact details, we can then enable local members (who are willing and interested) to meet up with other people who may live nearby.

Some members have also expressed an interest in receiving their Newsletter electronically. Some people will always prefer a paper copy, so this is not going to be obligatory. If you feel you would like to receive your Newsletter as a PDF attached to an e-mail, please let us know. We will need to set up a secure system to manage this process. The printing process of the Newsletter remains one of our highest costs, but the number of issues printed does not affect the cost greatly. Receiving your Newsletter electronically does, however, save on postage, is a greener option and may well be much easier for some members to read.

## Forthcoming Meetings

**Saturday November 26th in the Boardroom at Addenbrooke's Hospital.** Doors will be open from 12.00, when we hope to have an Audiologist speaking. More details will be given at the AGM and in the next Newsletter.

## Directory

### AMNET

W. [www.amnet-charity.org.uk](http://www.amnet-charity.org.uk)  
E. [contact.amnet@btinternet.com](mailto:contact.amnet@btinternet.com)  
T. 01953 860692

A. The Old School House, The Green,  
Old Buckenham, Norfolk, NR17 1RR

### British Acoustic Neuroma Association (BANA)

W. [www.bana-uk.com](http://www.bana-uk.com)  
E. [admin@bana-uk.com](mailto:admin@bana-uk.com)  
T. 01246 550011

Freephone. 0800 6523143

A. Tapton Park Innovation Centre,  
Brimington Road, Tapton, Chesterfield,  
Derbyshire, S41 0TZ.

### Meningioma UK

W. [www.meningiomauk.org](http://www.meningiomauk.org)  
E. [support-enquiries@meningiomauk.org](mailto:support-enquiries@meningiomauk.org)  
(Patient information & support)  
[meningioma@ellapybus.greenbee.net](mailto:meningioma@ellapybus.greenbee.net)  
(Meningioma UK)  
T. 01787 374084

### The Brain Tumour Charity

W. [www.braintumouruk.org.uk](http://www.braintumouruk.org.uk)  
T. 0845 4500386

A. Brain Tumour UK, Tower House,  
Latimer Park, Chesham, Bucks. HP5 1TU.

### Action on Hearing Loss (RNID)

W. [www.actiononhearingloss.org.uk](http://www.actiononhearingloss.org.uk)  
E. [informationline@hearingloss.org.uk](mailto:informationline@hearingloss.org.uk)  
T. 0808 808 0123 (Info line - Freephone)  
Textline. 0808 808 9000

### British Tinnitus Association

W. [www.tinnitus.org.uk](http://www.tinnitus.org.uk)  
E. [info@tinnitus.org.uk](mailto:info@tinnitus.org.uk)  
T. 0114 250 9933  
Freephone Helpline. T 0800 018 0527

A. Ground Floor, Unit 5, Acorn Business  
Park, Woodseats Close, Sheffield S8 0TB

### Cambridgeshire Hearing Help (CAMTAD)

[www.cambridgeshirehearinghelp.org.uk](http://www.cambridgeshirehearinghelp.org.uk)  
E. [enquiries@cambridgeshirehearinghelp.org.uk](mailto:enquiries@cambridgeshirehearinghelp.org.uk)  
T / Text / Fax. 01223 416 141  
(Mon - Fri 9.30am - 12.30pm)  
A. 8A Romsey Terrace, Cambridge  
CB1 3NH

### Changing Faces

Support for people with temporary or long  
term facial disfigurement problems  
W. [www.changingfaces.org.uk](http://www.changingfaces.org.uk)  
E. [info@changingfaces.org.uk](mailto:info@changingfaces.org.uk)  
T. 0845 4500 275

### Facial Palsy UK

W. [www.facialpalsy.org.uk](http://www.facialpalsy.org.uk)  
E. [info@facialpalsy.org.uk](mailto:info@facialpalsy.org.uk)  
T. 0300 030 9333  
A. PO Box 1269, Peterborough, PE1 9QN

### Entific Medical Systems

Info about bone conducted hearing aids,  
particularly for single sided deafness.  
W. [www.entific.com](http://www.entific.com)

### Addenbrookes Hospital

**Neurotology & Skull Base Surgery Unit**  
[http://www.addenbrookes.org.uk/serv/clin/surg/neurotol\\_skullbase/surgery\\_profile1.html](http://www.addenbrookes.org.uk/serv/clin/surg/neurotol_skullbase/surgery_profile1.html)

### Addenbrooke Hospital, Clinic 10 ENT

T. 01223 217588  
Appointments. 01223 216561  
Fax. 01223 217559

## BANA Booklets

BANA has produced some booklets which may be of interest:

- The Facial Nerve & Acoustic Neuroma
- Headache after Acoustic Neuroma Surgery • Eye Care after Acoustic Neuroma Surgery
- Effects an Acoustic Neuroma can have on your memory, emotions, behaviour, executive functioning and energy
- Balance following Acoustic Neuroma

All these booklets are free and available from Alison Frank The Old School House, The Green, Old Buckenham, Norfolk, NR17 1RR

## Necessary Note

AMNET News is very appreciative of the opportunity to publish items relevant to the interests of acoustic neuroma and meningioma patients. This includes instances where members of AMNET have experienced relief, improvement, difficulties or otherwise and write to us of their experiences in order to pass on information for the interest and possible benefit of other members. However, AMNET cannot endorse proprietary products or be held responsible for any errors, omissions or consequences resulting from the contents of this Newsletter.

## AMNET Advisory Panel at Addenbrooke's Hospital, Cambridge

Dr David Baguley BSc MSc MBA PhD Principal Audiological Scientist. Kate Burton Consultant Radiographer in Neuro-Oncology. Indu Bahadur Skull Base Nurse Practitioner. Mr Robert Macfarlane MD FRCS Consultant Neurosurgeon. Mr David Moffat BSc MA FRCS Consultant in Otoneurological & Skull Base Surgery. Ella Pybus Co-director Meningioma UK and Trustee of BTUK. Mr N J C Sarkies MRCP FRCS FRCOphth Consultant Ophthalmic Surgeon.

Honorary President - Alison Frank 01953 860692. Chairman - Heidi Pratchett 01255 508070.

Treasurer - Carol Clothier 01582 529938. Newsletter Editor - Sally Hardy 01954 231363

Please consider writing for your newsletter. It can be anything you feel will be of interest to members from a few lines to a couple of pages. It all helps to make the newsletter more interesting. Email: [sally.hardy3@btinternet.com](mailto:sally.hardy3@btinternet.com) If you would like to make a contribution please telephone or email me.