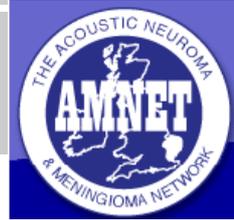


# AMNET NEWS



Issue 58 Spring 2014

**Autumn/Christmas Meeting  
Held at Addenbrooke's Hospital in the  
Boardroom on Saturday  
23rd November, 2013.**

**Presentation by  
Mr Neil Donnelly MSc (Hons) FRCS  
(ORL-HNS) Consultant Skull Base  
and Hearing Implant Surgeon,  
Addenbrooke's Hospital, Cambridge.**

We were very pleased to welcome **Mr Neil Donnelly, Consultant Skull Base and Hearing Implant Surgeon**, who had kindly agreed to come and speak to our members at our Christmas Meeting. Mr Donnelly told us that he would give a service update for Clinic 10, the Skull Base Unit at Addenbrooke's Hospital, Cambridge and that his talk would include developments in the multidisciplinary team over the last 4-5 years and what they are now able to offer. One very exciting new development is the establishment of a national database about vestibular schwannoma treatment. Developments about hearing rehabilitation and hearing implant surgery and details about on-going research and publications would also be discussed.



Mr Donnelly trained in London at Guy's Hospital and St Thomas's Hospital before going to Sydney, Australia to do a cochlear implant fellowship with Professor William Gibson. He then returned to Addenbrooke's to continue training in the Skull Base Hearing Implant Team alongside Mr Moffat and Mr Axon. He has been in post since 2009 and the Skull Base Team at Addenbrooke's Hospital now comprises the staff members featured in **Figure 1**.

During the last few years, the team have held multidisciplinary team (MDT) meetings fortnightly on a Friday morning, to discuss clinic appointments, to review patient MRI images and discuss likely treatment options. Patients are then seen that day in a one-stop clinic, where different specialists from ENT/Neurosurgery/Oncology are all present, and may meet more than one doctor at their appointment. The team in Cambridge is at the forefront in developing this service, which is in line with "IOG" (Improving Outcome Guidelines), and feel that by having an ENT and Skull Base perspective and having Neuro/Otology opinion in one place, they are able to offer a smooth service to patients.

Some details that were discussed are not yet published or at a developmental stage, and we were very grateful that Mr Donnelly was able to share information with members present at the meeting, but it is not possible to relay all the information here in print. The final slide of Mr Donnelly's presentation detailed recent publications by members of staff from Clinic 10, which are in the public domain, and can be seen at the end of this article, for those who would like to look further.

During the last few years, the team have held multidisciplinary team (MDT) meetings fortnightly on a Friday morning, to discuss clinic appointments, to review patient MRI images and discuss likely treatment options. Patients are then seen that day in a one-stop clinic, where different specialists from ENT/Neurosurgery/Oncology are all present, and may meet more than one doctor at their appointment. The team in Cambridge is at the forefront in developing this service, which is in line with "IOG" (Improving Outcome Guidelines), and feel that by having an ENT and Skull Base perspective and having Neuro/Otology opinion in one place, they are able to offer a smooth service to patients.

## Next Meeting

Will be on **Saturday 5th April, 2014** in the Boardroom at Addenbrooke's Hospital, Cambridge. Doors will open at 13.00 and the lecture will start at 13.30. Our speaker will be **Professor Brian C. T. Moore, Ph.D. F Med Sci. FRS**, Department of Experimental Psychology, University of Cambridge and his talk will be entitled: **"What you lose when you only have one working ear"**.

This is invaluable to many patients in view of the area served by Addenbrooke's Hospital.

**Figure 1. Skull Base Team at Addenbrooke's Hospital**

- **Mr Patrick Axon** MD FRCS (ORL), Consultant Skull Base and Hearing Implant Surgeon
- **Mr Neil Donnelly** MSc (Hons) FRCS (ORL-HNS), Consultant Skull Base and Hearing Implant Surgeon
- **Mr James Tysome** FRCS (ORL-HNS), Consultant Skull Base and Hearing Implant Surgeon
- **Mr Richard Mannion** PhD FRCS (SN), Consultant Neurosurgeon
- **Mr Robert Macfarlane** MD FRCS, Consultant Neurosurgeon
- **Dr Sarah Jefferies**, Consultant Oncologist
- **Professor Neil Burnett**, Consultant Oncologist
- **Mr Richard Price**, Consultant Plastic Surgeon
- **Kate Burton**, MSc (Hons), DCR(T), Consultant Radiographer
- **Indu Bahadur** RN, Skull Base Nurse Practitioner
- **Juliette Durie-Gair** RN BA (Hons), Skull Base and NF2 Nurse Practitioner
- **Nicola Folland** RN BA (Hons), Skull Base and NF2 Nurse Practitioner

(Information taken from Cambridge Skull Base Unit Patient Information document on Vestibular Schwannoma (VS) published March 2013 with minor amendment Nov 2013).

Mr Donnelly spoke of the importance of the Nurse Practitioner role – whereby a specialist medical member of the Skull Base team is available as a point of contact. There are currently 800 patients on the “Watch, Wait and Re-scan” protocol, and this number keeps increasing since 60% of vestibular schwannomas do not grow.

**National Vestibular Schwannoma Database**

As head of the Skull Base service, Mr Patrick Axon has been at the forefront of developing a national database for vestibular schwannoma data, to compare how many people are seen, what their treatment options were and to compare their outcomes. The information is currently submitted on a voluntary basis from units and is anonymous in data sets. This allows units to benchmark themselves against other units, but they do not know who the other data sets are from. This is an ongoing study and there is therefore no outcome data available. It is anticipated in the future that all units will submit all their cases and outcomes and that this data will be published publicly.

33 units were approached nationally and 16 units have submitted data. For the period 2010-2011 this comprises data from 969 patients. Addenbrooke's Hospital, Cambridge is the biggest single unit in the UK. A number of London hospitals sent their joint data for inclusion in the database. Other details compared in the database include details such as overall mortality rates (0.76% across all centres), CSF leakage rates and in-patient stay data.

Mr Donnelly informed us that in Cambridge, VS tumours are measured from the point where they extend out of the intracranial canal. He reported that patients with tumour present only within the intracranial canal were usually referred for “Watch, Wait and Rescan” (WWR), as were those with small to medium size tumours extending out of the intracranial canal. Those with larger tumours usually require surgery. A small number of patients convert from WWR to surgery or radiotherapy, either due to tumour growth, or because they are unable to tolerate WWR. Surgery for removal of a VS is usually done via the translabyrinthine approach, as they consider this approach safer for preserving the facial nerve and there is less chance of leaving any tumour in situ.

**Innovative New Technique for Anterior and Central Skull Base Service**

Mr Donnelly showed members present a number of slides which featured use of a 360 degree skull-based approach to the anterior and central base of the skull, which is especially useful when operating on the pituitary gland and surrounding area. The team use an extended endonasal approach to enter

the skull base via the nose and sphenoid sinus to the pituitary fossa. This technique involves two surgeons working together in tandem, which allows the surgeons to use their skills from lateral skull base surgery. Traditionally this type of surgery is done using a microscope, whereas in this approach, which uses an endoscope, the surgeon has a fuller view. In pituitary surgery, the team are now able to perform surgery using this endoscopic approach, which was not previously technically possible. They have audited their data for functioning pituitary tumours, which have previously needed expensive drug regimes, and can prove that this effective surgery can cut costs and improve patient outcome.

This technique can also be used for some anterior skull base meningiomas and this avoids the need to move the brain, and offers the possibility of achieving complete excision, with reduced side effects and recovery rates.

### **Hearing Rehabilitation Developments**

A standard BAHA (bone anchored-hearing aid) involves a titanium screw being implanted into the skull and due to it being made of titanium, the body does not reject the device. A transcutaneous [through the skin] abutment connects this by vibration, to a hearing aid, which is worn behind the ear. This type of device is useful for those with congenital ear abnormalities and those unable to wear a standard hearing aid. It is also useful for conditions like otosclerosis, [a condition of the middle ear that leads to hearing loss], and has been used for single sided deafness. There has been a slight problem in the past with infection at the site of the abutment, where it sticks through the scalp. To help with this problem, an alternative device that relies on bone conduction has been developed; this Bonebridge device has two parts – an implantable internal vibrational part and an external speech processor. This new device can be used to replace the standard BAHA. This development is so new that it has only just become a possibility. The Skull Base Unit is a centre of specialism in SSD, and national funding for this procedure is now available, whereas previously it was not.

### **Cochlear Implants**

These are used to stimulate the nerves of the cochlear directly, where the delicate hair cells that translate sound wave movement into an electrical

signal have been damaged. This type of device can allow deaf children and adults to attain hearing by stimulating the hearing nerve. Cochlear implants have been used for deaf children and adults around the world and in Cambridge they have also been used for those with single-sided deafness who have developed a vestibular schwannoma in their only hearing ear and where the tumour has not grown. Results have been promising and are particularly useful for those using lip-reading and open-set speech. Cochlear implants are tuneable, so high or low-frequency changes can be adjusted.

### **Research Developments**

The next new ground-breaking development will be in vestibular implantation, which could offer the possibility of improved balance. This will be a pioneering field of surgery, but technically difficult, since there are five elements to the balance system. Addenbrooke's Hospital has recently received ethical approval to research certain elements of this. There is a need to develop the vestibular implant and the surgical technique to implant the device, without harming another nerve. It is hoped to seek approval from patients having surgery for removal of a VS, who have measurable balance and hearing before surgery, to be involved with this research. As the patient will currently lose this nerve during VS surgery, then monitoring during surgery can help in research without causing any harm to the patient. However, the patient taking part in this research would not currently be able to benefit from the device.

### **Publications**

Mr Donnelly then reported on recent publications by the Skull Base Unit, including one on 30-year research on squamous cell carcinoma of the temporal bone. Please see the list of publications that follows if you would like to read any of the publications.

Alison Frank, our Chairman, thanked Mr Donnelly for giving up his Saturday afternoon to come and speak to us. All members present were extremely grateful and I hope that our readers will find this account of Mr Donnelly's talk to us both interesting and informative.

Communications course details on page 4.

## Recent Skull Base Unit Publications List

### **Squamous Carcinoma of the Temporal Bone: Lessons learned over the past thirty years.**

Masterson L, Rouhani M, Donnelly N, Tysome JR, Patel P, Jefferies SJ, Scrase C, Mannion R, Macfarlane R, Hardy D, Durrani A, Price R, Marker A, Axon P, Moffat DA.

*Otol Neurotol.* Accepted for publication

### **English consensus protocol evaluating candidacy for auditory brainstem and cochlear implantation in neurofibromatosis type 2.**

Tysome JR, Axon PR, Donnelly NP, Evans DG, Ferner RE, O'Connor AF, Freeman SR, Gleeson M, Halliday D, Harris F, Jiang D, Kerr R, King A, Knight RD, Lloyd SK, Macfarlane R, Mannion R, Mawman D, O'Driscoll M, Parry A, Ramsden J, Ramsden R, Rutherford SA, Saeed SR, Thomas N, Vanat ZH.

*Otol Neurotol.* 2013 Dec;34(9):1743-7.

### **Cochlear implants to treat deafness caused by vestibular schwannomas.**

Mukherjee P, Ramsden JD, Donnelly N, Axon P, Saeed S, Fagan P, Irving RM.

*Otol Neurotol.* 2013 Sep;34(7):1291-8.

### **Outcome of translabyrinthine surgery for vestibular schwannoma in neurofibromatosis type 2.**

Moffat DA, Lloyd SK, Macfarlane R, Mannion R, King A, Rutherford S, Axon PR, Donnelly N, Freeman S, Tysome JR, Evans DG, Ramsden RT.

*Br J Neurosurg.* 2013 Mar 8

### **Surgical management of vestibular schwannomas and hearing rehabilitation in neurofibromatosis type 2.**

Tysome JR, Macfarlane R, Durie-Gair J, Donnelly N, Mannion R, Knight R, Harris F, Vanat ZH, Tam YC, Burton K, Hensiek A, Raymond FL, Moffat DA, Axon PR.

*Otol Neurotol.* 2012 Apr;33(3):466-72.

### **Cochlear implant failures: lessons learned from a UK centre.**

Masterson L, Kumar S, Kong JH, Briggs J, Donnelly N, Axon PR, Gray RF.

*J Laryngol Otol.* 2012 Jan;126(1):15-21.

## AMNET Communications Course



Chris Richards then gave us the following account of the Communications Course which took place at Ad-denbrooke's in September, 2013.

“The course was designed for members who felt they may like to know more about how to support enquirers to the organisation. All enquiries are directed to one number at present, but the Committee felt it would be good to have a group of members who would be willing to talk to people enquiring, particularly if they have some common ground.

The workshop was led by Alison Frank and Chris Richards and was attended by 8 interested members of AMNET. The workshop was built around considering what people wanted when they contact the organisation and how we can develop our communication skills and understanding about decision making, in order to provide the most appropriate support for those who do contact us.

We discussed what we felt people contacting AMNET were looking for and made a list. We then considered the importance of how we communicate with people in our daily lives, thinking about what influences how effective communication is, how well we listen, using questions and the importance of body language. We also considered how some of these factors may need to be adapted when using a telephone or e-mail. We also thought about how people make decisions and the processes that can be used to help people work through making difficult decisions.

At the end of the session we drew up some guidelines that we felt would support members who were involved in talking to people who contact us when they or a family member have a diagnosis of a skull base tumour. These guidelines will need to be kept under review, along with sources of information that we may feel happy to pass on to enquirers.”

Chris Richards

Chris then made merry with our annual Christmas Raffle. There were many donated prizes to be won and we were very grateful to those who kindly donated these and to everyone who supported us by buying a ticket. Most people went home with a prize and we raised the sum of £45 for AMNET funds.

## Hearing Notes

A tale of how we cope  
by AMNET members Sue and  
Roger Mansfield



Some while after my operation and whilst still getting used to my one-sided hearing, my mother-in-law was taken very ill and we had to look after her. This resulted in her ringing us at any time throughout the night. Because my husband is hard of hearing, and with me sleeping on my deaf ear, we missed a number of calls at night, which was distressing for her and we felt bad because we let her down.

When I had the next follow-up consultation with the hospital, I mentioned this. It was suggested that a member of the Social Services come and talk to us to see if there was anything they could do to help the situation. A very polite and helpful consultation eventually took place, which resulted in me being equipped (by Sensor Services) with a device that acts as an alarm clock. This was fitted by my bed with a vibrating pad that sits under my pillow at night. This device is called a "Lisa RF Time Flash" (and for those interested, is manufactured by Humantechnic, Model No A-3241-3). This in turn connects remotely (by wi fi, I think) to the phone, doorbell and smoke alarm - all of which are fitted with sensors that send a signal to the alarm, which goes off when any of the items are activated. As well as this, the pad under my pillow vibrates and wakes me up - the result of which means we now never miss a call.

Another piece of equipment was also provided, which really improves the quality of sound from the television. This is a wi fi headset, but **not** the type you can buy in the high street shops, which only operate in stereo and are no good for those with single sided hearing, because you can only hear half of what is broadcast. The equipment that I have is an "Infralight DIR Headset system". You can switch this system to MONO which means that you can hear all the dialogue and everything seems crystal clear. I believe you can purchase these on the internet. If you think you would like to try one of these, I would suggest that you make sure that the equipment still switches to mono, in case they have changed the specification.

**Sue Mansfield**

## CAMTAD – New Name is Cambridgeshire Hearing Help

As from 1<sup>st</sup> January, 2014 CAMTAD will be known as **Cambridgeshire Hearing Help** and their website has changed to **cambridgeshire-hearinghelp.org.uk**. I have changed our reference section on the back page accordingly. There will no change to the services they provide or to their telephone number or office. Please go on-line to find out when their nearest session is for your community access for hearing aid batteries for 2014, or telephone: 01223 416 141 if you do not have a computer.

With reference to the last article by Sue Mansfield, you might like to know that Cambridgeshire Hearing Help lend equipment for a month from their Cambridge office, so people can try before they buy and get an idea of the benefits that new equipment may bring. There will be **demonstrations of hearing help equipment** and a chance to view and try telephones, TV amplifiers, alerts and more on:

**Friday 21<sup>st</sup> March 2014** at

Scotsdale Garden Centre, Great Shelford from 10.00-12.30 on a drop-in basis.

**Wednesday 24<sup>th</sup> September 2014** at

St Peters Church, High Street, March From 10.00-12.30.

**Thursday 27<sup>th</sup> November 2014** at Ely Cathedral Centre, Palace Green Ely.

Also **Equipment information sessions** on:

**Thursday 8<sup>th</sup> May 2014** at

Age UK Ambury Day Centre, Huntingdon 19.00-12.00.

**Wednesday 27<sup>th</sup> August 2014** at

The Old School, Bassingbourn from 14.00-16.00.

**Thursday 9<sup>th</sup> October 2014** at Royal British Legion Hall, 122 High Street, Cottenham from 14.00-16.00.

**19th - 25th May 2014 is Deaf Awareness Week**

For referral to the local authority and Sensory Services team for an assessment of need and provision of assistive equipment (as mentioned by Sue), please phone: 0345 045 5221.

## *My deaf ear*

A poem by Helen Bush

You'd never know, it looks the same  
As all the other ones you see,  
But my right ear has a life of its own,  
Belonging, and really special, to me.

For many years it served me well,  
My balance fine for a life in sport,  
Throughout my youth my hearing great,  
Much later things became more fraught.

Some years ago came hearing loss,  
Insidious worm invaded brain,  
Neuroma made its way across  
And way beyond its own domain.

Tumour gathered strength to grow,  
Pressure put on nerves so deep,  
Balance worsened, such a blow,  
Sometimes just relief to sleep.

Tinnitus is such a blight,  
Constant now but not before,  
Rushing, hissing from the right  
Masks the hearing even more.

Vestibular schwannoma lives  
Inside my head, tucked out of sight,  
Advice and treatment sometimes gives  
Hope for future on the right.

But now -  
Orientation up the creek,  
Difficulties hearing people speak,  
Often feeling drunk and weak,  
Future sometimes seems quite bleak  
With my deaf ear.

Something worth the living for,  
Music helps to combat fear,  
Singing always lifts the soul,  
Oh so precious, my left ear.



**Helen Bush, January 2014**

## Update on new development re eye drops from donated blood Can *you* help?

Further to my report in the last Newsletter on a feature by BANA about Dry Eye Syndrome (DES) in *The Blood Donor*, a magazine produced by NHS Blood and Transplant Service, I am afraid there has been little progress to date. I contacted them on their website and left an enquiry on their "Contact us" section. I then tried to ring the Cambridge Branch in Long Road, Cambridge – as there was no-one to speak to, I left an answerphone message and asked for someone to call back. I did not receive a call back. I wrote to the same address weeks ago, and sadly have heard nothing. Rather than give up, I will write to *The Donor* magazine now and ask there.

Are any AMNET members regular blood donors? If so, would you be prepared to ask about this facility at a blood donor centre when you are there to give a blood donation? Apparently blood that is to be used to prepare artificial tears needs to be collected in a special type of blood pack, so it is possible that not all centres would be able to offer this facility.

Sally Hardy, Editor

## ***"Decompensation"* – a symptom you may have experienced and perhaps not understood.**

One of our members wrote to suggest that it might be interesting to feature an article on the subject of "**decompensation**". This is a symptom which *may* be experienced by patients who have had surgery for the removal of a vestibular schwannoma. Our member had his vestibular schwannoma removed by Mr Moffat in 2005. He recently suffered concurrent ear and chest infections, with resulting temporary hearing loss and more persistent balance loss. The balance problem was almost as bad as that he experienced when going home from the surgery. Unsteady on his feet, with the world spinning, he could only walk very short distances. He therefore saw

Mr Moffat, who said that his balance had “*decompensated*” and recommended that he saw a physiotherapist for balance exercises.

The term “*decompensation*” was one which none of us on the Committee at AMNET had heard of before, so I checked with various staff members in Clinic 10 and Juliette Durie-Gair forwarded the following reply from Mr Moffat, who is happy for his reply to be featured here in case it is of interest to members of AMNET.

The three sensory inputs to the central vestibular system are:

**the labyrinth,  
eyesight  
proprioception**

[For those who need a little explanation here: the **labyrinth** is in the inner ear and comprises:- a) the cochlea – this relays sounds to the brain, and b) the vestibular system – a complex set of fluid-filled channels responsible for sense of balance; and **proprioception** refers to the body’s ability to sense movement within joints and joint position, which enables us to know where our limbs are without having to look at them. In the paragraph that follows: **ipsilateral** means located on the affected or same side of the body and **caloric response** – rapid, side to side eye movements should occur when cold or warm water is placed into the ear and the eye movements should be similar on both sides].

A vestibular schwannoma (and other causes of unilateral loss of labyrinthine function) reduces the neural input to the central vestibular system from the ipsilateral labyrinth (80% of those with a vestibular schwannoma, or surgery for removal of this type of tumour, have an absent or grossly reduced caloric response) and the brain “*compensates*” with eyesight (optic fixation) and proprioception. Some patients do not “*compensate*” very well for the unilateral loss of vestibular function and this produces disequilibrium and *can* cause, less commonly, rotary vertigo. This can be brought on by stressing the vestibular system by rapid head movement (either linear or angular acceleration), mental and physical fatigue. At these times the brain cannot cope –

“*decompensation*” occurs and the patient has disequilibrium or vertigo.

I always give an analogy to my patients:

Think of an aeroplane with one engine not-working (loss of labyrinthine function), the plane will turn to the side of the non-working engine and the fin and flaps straighten up the plane. The fin and flaps of the aircraft are like the “brain” which “*compensates*” for the unilateral loss of vestibular function. If it fails to do this then the patients are poorly compensated for the unilateral loss of vestibular function, or they may have compensated for most of the time and “*decompensate*” when the vestibular system is stressed in the way I have described.

**Mr David Moffat** BSc MA FRCS  
(former Consultant in Otoneurological and Skull Base Surgery)

We are very grateful to Mr Moffat and members of staff in Clinic 10 at Addenbrooke’s Hospital, who have helped in clarifying this term for us.

Six months after surgery for removal of a vestibular schwannoma, I experienced symptoms like our member reports above. This was following a heavy cold and my work as a Practice Nurse had been busy and challenging through the winter season. I was wearing my family out with my almost hyperactive will to live life to the full. My GP diagnosed labyrinthitis and advised me to rest and download “**Vertigo Rehabilitation Exercises**” using the “*Cawthorne-Cooksey*” treatment. This article by Mr James W Fairley BSc MBBS FRCS MS Consultant ENT Surgeon, is available at:

entkent.com/Cawthorne-Cooksey.html#vertigocceercises,  
or Tel: 01233 642244 if you do not have access to the internet.

Although I subsequently found out that the labyrinth is removed during the process of surgical removal of a vestibular schwannoma using the *translabyrinthine approach* – the preferred surgical approach at Addenbrooke’s, used to preserve facial

nerve function and less chance of leaving any tumour in situ - it is likely that most GPs will be unaware of this fact when they examine your ear in a GP consultation. I therefore could not possibly have been experiencing labyrinthitis at the time. Maybe it is obvious to many readers that the labyrinth would have been removed in this surgical approach, but it wasn't obvious to me, so I thought it worth pointing out.

The information in the "Vertigo Rehabilitation Exercises" includes simple eye and head exercises – some of which are done sitting and some standing and then progressing to exercises whilst moving. It is suggested in this article that the *commonest situations* where you may get a **recurrence of vertigo symptoms** are:

- sudden rapid movements
- in the dark
- on soft or uneven ground
- under the influence of sedative drugs or alcohol
- fatigue
- infection

This current article has been reviewed by Helen Hewlett, Senior Physiotherapist in the Neurosciences Department at Addenbrooke's Hospital, and she has reassured me that the exercises referred to above are similar to the information given out by them. It would be interesting to hear from other members about any other exercises that they have found helpful.

I do hope this has helped, but if you continue to have balance problems you may need to see your GP for a physiotherapist referral. Balance is clearly a complex issue, as Mr Donnelly pointed out when talking about vestibular implants. As there are five elements to the balance system, some people who experience problems with their other senses, like vision, may need referral to other specialists.

In my own case, by slowing down a little, I found improved confidence in movement and the "Vertigo Rehabilitation Exercises" helped me understand the changes in my body - and that understanding went a long way to accepting those changes and viewing physical challenges in a different way.

Sally Hardy, Editor

## News from the British Tinnitus Association

**Tinnitus Awareness Week** is being held from 3<sup>rd</sup>-9<sup>th</sup> February, 2014, so will probably have happened by the time you get this newsletter. I will update you in a future edition about any news this generates.

In the meantime I thought you might be interested to know that there will be two **British Tinnitus Information Days** in 2014. There are currently "free places" available, to register interest in attending please contact:

**Krys Klytta**, on Tel: **0114 250 9933**  
or e-mail: [krys@tinnitus.org.uk](mailto:krys@tinnitus.org.uk)

The events will be held on:

**Saturday 15<sup>th</sup> March 2014** at: Park Plaza Hotel, Boar Lane, City Square, Leeds LS1 5NS

**Saturday 14<sup>th</sup> June 2014** at: Thistle Hotel, Kings Road, Brighton BN1 2GS.

I also noticed that there is a local support group in Cambridge - **Cambridgeshire Tinnitus Support Group**. They hold 5 meetings per year, which take place the Meadows Community Centre, 1 St Catherine's Road, Cambridge (which is off the junction between King's Hedges and Arbury Rd). Future meetings include:

**Saturday 19th April 2014**

AGM and presentation by Phil Gomersall MSc CS, [who you may have met in Audiology] entitled: "What can be done if you are deaf in one ear".

**Saturday 21st June 2014** Two presentations - Kathryn Fackrell: "Evaluation of a new tinnitus questionnaire - how effective is it at picking up characteristics or changes in someone's tinnitus". Kate Greenwell: "Looking at the effectiveness of different self-help programmes for people with tinnitus". Both Kathryn and Kate are based at Nottingham Hearing Biomedical Research Unit.

For more details, and if interested in attending one of the talks: contact **Alan Yeo** at:

**mga978@hotmail.co.uk**

or Tel: **01223 243570**

## Editorial



I have been so encouraged again by your response, and contributions to this Newsletter. I also wish to express my sincere thanks for the helpful response there has been from many members of staff from Addenbrooke's Hospital in the preparation of this Newsletter, both amongst consultants and other staff members from Clinic 10. Some articles may appear long, but I felt it necessary to include relevant information, especially in the ground-breaking features discussed by Mr Donnelly. I hope you will enjoy Helen Bush's poem, as I did, and find the information from Sue Mansfield useful in making your hearing experience at home one where you do not miss a telephone call that might be so important. Please do keep your articles/ideas coming, and also any "Helpful Hints" that you may wish to share. It has been really interesting to help our member find out more about decompensation - if there is a subject that you would like a bit of help to understand, please ask as information generated may benefit other members too.

Our meeting on 21<sup>st</sup> June will be preceded by our AGM, details of which will be sent out with the next Newsletter. If you feel that you might like to be more involved, either by considering being on the Committee, or by helping with research, the website or whatever you might think would add to supporting others within the organisation, please contact Alison Frank, (Tel: 01953 860692).

Could I put in a personal plea with regards to the Newsletter. My own neuroma is needing on-going monitoring with potential treatment. At the last Committee Meeting we felt it would be relevant to consider having a Sub-Editor, or someone who can help with writing/trawling the internet for articles and be prepared to write articles. If you would like to discuss this, please contact either Alison Frank, or myself (Tel: 01954 231363; e-mail: [sally.hardy3@btinternet.com](mailto:sally.hardy3@btinternet.com)).

Sally Hardy, Editor

## New repair times at the Addenbrooke's Hospital Audiology Open Access Hearing Aid Repair Clinic

In their December 2013 Newsletter, Cambridgeshire Hearing Help listed new repair times in the above clinic:

**New repair times (as of 1<sup>st</sup> December 2013) are as follows:**

Monday	9.00 - 12.00
Tuesday	1.30 - 5.00
Wednesday	9.00 - 12.00
Thursday	1.30 - 5.00
Friday	9.00 - 12.00

## News from BANA

AMNET is a sister organisation to BANA, so I would like to inform you of their recent administration changes. Some of the people mentioned have attended AMNET meetings and visited us for the BANA AGM held at Addenbrooke's Hospital in July 2006 (yes, it was that long ago!).

Kevin Dimmelow has retired as Chairman, but will stay as a Trustee and Janet Mercer, who has been Vice Chairman since 2009 will succeed him. Caryll Petersen, one of the founders of BANA in 1992, has stood down as a Trustee. Jackey Weightman, who with her husband Alan has attended quite a few of our meetings, has also retired as a Trustee, but is still involved in BANA administration and producing BANA Headline News.

BANA have also appointed a Chief Executive Officer, Debra Key. She is not a vestibular schwannoma patient, but has experience working in business administration and management, some in the private medical field and specialist mental health administration. Debra hopes to raise BANA's profile and to increase its income from fundraising and grant applications.

AMNET Committee and members wish BANA well with these constructive changes.

Alison Frank, Chairman

## Patient Representative role for the Skull Base Team at Addenbrooke's Hospital, Cambridge.

In Issue 56, Summer 2013 of AMNET News, I mentioned that I had been approached by Juliette Durie-Gair, one of the Nurse Practitioners from the Skull Base Team, to see if any members of AMNET would be prepared to act as "Patient Representatives" for the team and attend meetings. The Anglia Cancer Network oversee the provision of Skull Base Services within ENT, Neurosciences and Oncology, and is itself part of the Strategic Clinical Network. Patient representation, as part of the "patient and carer" involvement, is welcomed and appreciated by both Addenbrooke's Hospital and the Strategic Clinical Network. As Patient Representatives for the Skull Base Team, this role entails being representative of **all** patients covered by the services provided by skull base services at Addenbrooke's, including vestibular schwannoma treatment.

In the Patient Information document given out to newly diagnosed vestibular schwannoma patients (March 2013), the Skull Base Group state:

"We are keen to hear what you have to say about the service, and where possible, wish to involve you in service development, so that we can provide the best patient-focused care possible".

There are now two Patient Representatives in the Skull Base Team, who attend meetings, which take place at Addenbrooke's twice a year. Alison Parkes and Sally Hardy have now attended two meetings which have been held in Clinic 10 at Addenbrooke's, chaired by Mr J Tysome, Consultant Skull Base and Hearing Implant Surgeon. In these meetings, service development is discussed and our role, to date, has included revision of the Patient Information document (mentioned above). A future project will involve assisting with a Patient Experience Questionnaire that Clinic 10 are formulating, which will review patient-focused care from point of diagnosis of vestibular schwannoma through to one year post-discharge from surgery.

At the last meeting, one of the consultants present asked whether there were any issues to discuss from AMNET members. Alison and I will be available at AMNET meetings if there is anything you would like to talk to us about. We would like to feel that those of you who are unable to attend meetings also have the possibility to contact us, should you wish to suggest an issue for discussion about provision of services by the Skull Base Team in your experience in Clinic 10.

We thought a little background about ourselves might help. Both Alison and I have had surgery at Addenbrooke's for removal of a vestibular schwannoma. Alison is in her early 30's, she is married and has two small children. She is a part-time Occupational Therapist and lives near Stansted Airport. I am 59, married and have two children and two grandchildren. I live 12 miles north of Cambridge and am recently retired from nursing.

Our contact details are:

**Sally Hardy** – 01954 231363  
or e-mail: [sally.hardy3@btinternet.com](mailto:sally.hardy3@btinternet.com)

**Alison Parkes** – 01279 310877  
or e-mail: [allyj80@yahoo.co.uk](mailto:allyj80@yahoo.co.uk)

## Resignation from AMNET Committee Secretary needed

Our current Secretary, John Peartree, has resigned from the AMNET Committee. John has been a valued member of the Committee and we are all grateful for his steadfast efforts which he has given freely over the years. This means that there is currently a vacancy on the Committee for a Secretary. At present this role is being maintained by Chris Richards, our former Editor. Is this a role you would consider taking on? Nominations for office will need to be in place before our AGM in June, 2014, so if you think you might be interested please contact Alison Frank, our Chairman, on: 01953 860692.

## Joint Membership for Current AMNET Members

We recently had a request from a new member for their partner to join AMNET as a member also. As a result we can now offer joint membership at a cost of an additional £5.00, i.e. £20 per annum.

This gives the right to vote on any AMNET issues to both people and also entitles both to become committee members if they so desire. If your partner wishes to become a member please let us know. Please note there is no charge for partners who attend the meetings but have not taken up membership.

Carol Clothier, Treasurer

## Would you like to join AMNET?

AMNET is a sister organisation of BANA, the British Acoustic Neuroma Association. We represent the Eastern Region of the UK.

*We provide:*

- Telephone contact with past patients, who understand what you are going through, and have time to listen.
- A regular newsletter for members, with information about developments in treatment and about living with an acoustic neuroma (now called vestibular schwannoma).
- Regular meetings at Addenbrooke's Hospital, Cambridge where we provide an opportunity to listen to expert speakers and to meet other members.
- A detailed website at: [www.amnet-charity.org.uk](http://www.amnet-charity.org.uk).

If you would like to join AMNET and support our work, please complete the form below and send £15 annual subscription to Alison Frank at the address listed. We can now offer joint membership at a cost of an additional £5.00, i.e. £20 per annum. This gives the right to vote on any AMNET issues to both people and also entitles both to become committee members if they so desire. If your partner wishes to become a member please let us know. Please note there is no charge for partners who attend the meetings, but do not take up membership.

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Please complete the form below and send with your annual subscription for £15 (or £20 if you wish to take up joint membership) to Alison Frank and address your envelope: AMNET, The Old School House, The Green, Old Buckenham, Norfolk. NR17 1RR

Please tick one of the following:

Are you currently deciding on treatment option?

If you have already opted for a treatment option, which treatment did you choose?

Microsurgery       Radiotherapy   
Radiosurgery       Watch, wait and rescan

Name:

Address:

E-mail:

Telephone:

I enclose a cheque for £15 for my yearly subscription to AMNET. If you would welcome the chance to speak to another AMNET member on a one-to-one basis, please could you telephone our Chairman, Alison Frank, (Telephone: **01953 860692**), who will be able to put you in contact with one of our members.

## Forthcoming Meetings

**Summer Meeting** - We hope to have some from the Eye Department at Addenbrooke's to speak at this meeting, which will probably be on **Saturday 28th June, 2014** (but may need to be 21st June). Date and speaker to be confirmed in next Newsletter.

The **Autumn Meeting** will now be on **Saturday 22nd November, 2014** and our speaker will be **Kate Burton, Consultant Radiographer in Neuro-Oncology, Addenbrooke's Hospital** - title to be announced in 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. 01623 632143

Fax. 01623 635313  
Freephone. 0800 6523143

A. Oak House B, Ransomwood Park,  
Southwell Road West, Mansfield, Notts,  
NG21 0HJ

### 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. [infor@tinnitus.org.uk](mailto:infor@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

(formerly CAMTAD) W. [www.cambridgeshirehearinghelp.org.uk](http://www.cambridgeshirehearinghelp.org.uk)  
E. [admin@camtadcamb.org.uk](mailto:admin@camtadcamb.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:

- A Basic Overview of Diagnosis & Treatment of Acoustic Neuroma • 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 available from Alison Frank The Old School House, The Green, Old Buckenham, Norfolk, NR17 1RR  
There is a £2 charge for all books.

## 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

**Mr David Baguley** MSC MBA 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.

Chairman-Alison Frank 01953 860692. Treasurer- Carol Clothier 01525 404266

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.