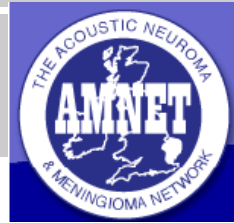


AMNET NEWS



Issue 62 Summer 2015

AMNET needs your help!



This year AMNET is celebrating 19 years of supporting our members and others.

AMNET was set up to support people who had been diagnosed with acoustic neuromas or meningiomas, and their families, and was focused mainly on Addenbrooke's Hospital and the East of England.

Much has changed since we started up in 1996, both in terms of the way skull base tumours such as acoustic neuromas are managed, and also in the way charities are organised and run. Two of our longstanding trustees - **Alison Frank and Chris Richards** - are stepping down from their roles this year and if we are to continue as an independent organisation, *we need some new trustees with ideas and enthusiasm, who will be actively involved in the running of AMNET*, so we can continue to provide the level of support deserved by existing and future members

We feel that AMNET is at a crossroads, and that as we move into our 20th year we need to acknowledge that the world is changing and we need to change with it.

AMNET is in jeopardy if people do not step up and help us.

If you would like to help please contact Alison Frank or one of the other committee members as soon as possible. Please see back page for contact details.

Our Next Meeting will be on **Saturday 11th July, 2015** in the Boardroom at Addenbrooke's Hospital, Cambridge. Doors will be open at 12.00 and a light lunch will be provided before our **AGM**, which will commence at 12.45. *Please make sure your views are made by attending this vital meeting or by using your proxy vote.* This meeting will be followed by a presentation by **Debra Nash, CEO of BANA.**

Our Spring Meeting

was held in the Boardroom at Addenbrooke's Hospital, Cambridge on Saturday 18th April, 2015 and featured a presentation by

**Mr James Tysome, MA, Ph.D,
FRCS (ORL-HNS),**

Consultant Skull Base and Hearing Implant Surgeon and Clinical Lead of the Skull Base Team at Addenbrooke's Hospital Cambridge.

Improving Our Skull Base Service

All of our members present at the Spring Meeting were able to experience an open and interactive presentation with Mr James Tysome, who is Clinical Lead in the Skull Base Team (Clinic 10) at Addenbrooke's Hospital, here in Cambridge. He very generously came and gave his presentation to us on a gloriously sunny Saturday afternoon – direct from his own son's 5th Birthday party!

He began by thanking us, as a group, for our interest - he assured us this is welcomed by the whole multidisciplinary team and added that any feedback is welcome, as that is how change happens.

In writing this report, I have included information from my personal experience of hearing rehabilitation and information gleaned from attending the Lip-reading Course at Addenbrooke's Hospital, which is run by Audiologist Joy Badcock. Please also see an article by our member, David Brown in this Newsletter, (p 4), in which he gives experience of “**real ear measurements**” in the setting up of digital hearing aids. I also refer to the article by Mr Donnelly in Issue 58 of AMNET News (Spring 2014), so you might like to refer to that article alongside this one.



Mr James Tysome

Background

Mr Tysome read undergraduate medicine at Cambridge University and University College London. His postgraduate training included advanced otology and hearing implants at Guy's and St. Thomas' Hospitals, paediatric ENT at Great Ormond Street Hospital, a fellowship in neurotology and skull base surgery at Cambridge University Hospitals in 2010 and working as a Clinical Instructor at Stanford University School of Medicine in California, USA, (which is one of the biggest referral centres for skull base treatment), where he gained further experience of skull base surgery, cochlear implants and robotic surgery.

Aims of the skull base service

The primary aim is to provide the **highest level of care for patients using the skull base service.**

This is done by having:

- multidisciplinary team approach to care
- close monitoring and review of patient referral pathways
- offering sub-specialist care services and a 360 degree approach
- monitoring on-going training needs of the whole skull base team
- keeping up to date and participating in research

The **Manual for Cancer Services for Brain and CNS** (central nervous system) provides guidelines for how the service should be delivered. There is a peer review process that measures and reviews the service as a whole and how it is being managed. Mr Patrick Axon led the development of the National Audit for Vestibular Schwannoma - the first audit has been done and results will be published soon.

Detail of Service Review

Mr Tysome shared with us details of the skull base team **National Peer Review** details, which ranked the Cambridge team at 57% in 2013 and 86% in 2014 – a figure which is hard to beat in reality. The team are meeting all cancer targets. Two Patient Representatives have been appointed and attend meetings twice-yearly, with an aim to improve patient information. The team have recruited a Clinical Neuropsychologist and a Neuropsychiatrist. **All MRI scans for WWR** (watch, wait and re-scan) patients, and pathology from surgical patients are

discussed in multidisciplinary meetings held every two weeks in Cambridge. These two-weekly multidisciplinary meetings are linked up (via video-conferencing) with other hospitals in East Anglia, which include Kings Lynn, Norwich and Ipswich. Some patient-needs cross between disciplines of health care provision and in these cases surgical leads attend multi-group meetings, e.g. skull-base/NF2/CNS/head and neck.

Training and Research

Besides training skull base surgeons, the team has both ENT and neurosurgery fellowships for those surgeons who have finished their training, but want specialist training – as Mr Tysome did himself at Addenbrooke's. They run advanced otology, neurosurgical and anatomy lectures, both here and abroad. They attend conferences in the UK and abroad, where Mr Axon, Mr Donnelly and Mr Tysome keep up to date and disseminate their knowledge. The team have published 20 publications over the last 3 years and supervised 3 MPhil students over the past 2 years. A tissue bank of excised VS (vestibular schwannoma) tissue will give the team material to develop their research into the biology and genetics of this type of tumour. One of Mr Tysome's research interests is in developing novel targeted treatments and molecular imaging techniques for skull base tumours.

The team recruit to all appropriate skull base trials. As discussed by Mr Donnelly, when he visited us last year, the skull base team are now proceeding with their trial to develop vestibular prosthesis implantation. They are also contributing to a trial to assess *the possibility of regeneration of cells of the balance system through stem cell research*. They are also investigating vestibular implants. With consent, patients undergoing VS surgery undergo pre-surgical testing to assess their balance level. A vestibular implant is then inserted into the balance system and measurements of eye movements and brain response taken before it is removed to continue with the operation as normal. They have gained valuable knowledge in this area.

We were given reassurance that *as many as 65% of small VS tumours* (up to 15 mm in diameter in the intracranial space) *never grow*. Those tumours in the younger population and larger tumours are more likely to grow. Therefore a **primary aim of the team is to understand the genetics of this type of**

tumour and its growth, in order to provide an answer. Currently in use in NF2 patients in England, Bevacizumib has been shown to limit angiogenesis [blood vessel formation] of tumours by targeting a compound VEGF (which correlates with tumour growth) and therefore acts as a monoclonal antibody to stop tumour growth. This has resulted in the majority of previously fast growing tumours remaining stable. The effect of this has been the need for fewer surgeries each year for this type of tumour. Bevacizumib is an expensive compound and is solely used in the NF2 groups of patients, who are likely to have bilateral VS tumours and tumours elsewhere in the cerebrospinal system. **By understanding the disease process, it can lead to improvements in future treatments.**

Rehabilitation after VS surgery

Hearing – Following VS surgery, patients are fully supported with their rehabilitation through the single-sided deafness expertise of the audiologists within Clinic 10. Both before and after surgery, an audiologist will work with each individual to assess hearing, with the experience and expertise of dealing with individuals who experience sudden loss of hearing on one side, and the quality of life issues this may bring with it.

After an initial recovery period following VS surgery, patients are invited back to try a cross-aid, usually one with a connecting wire, which has a microphone that is fitted to the deaf side to relay sound to a receiver worn in the hearing ear. For those with hearing impairment in their remaining ear, the receiver will act as both receiver/hearing-aid for the hearing ear. When fitting the hearing-aid, the audiologist will work with each individual with the aim of providing the highest quality of sound being transmitted from the deaf side, with an emphasis on the sounds of the human voice. As David Brown discusses (see p 6), when the "real ear" procedure is used by the audiologist in setting up a hearing aid for a person's requirements, this provides a more scientific assessment using a wide range of sounds and removes the subjective element. Depending on progress with this device, patients are then offered a wireless digital device, which is funded by the NHS.

The BAHA (bone anchored hearing aid) is also an option for hearing rehabilitation for those having VS surgery. *Due to changes in national commis-*

sioning, this has now been funded through the NHS for single-sided deafness. This will only be offered to those with residual hearing in the good ear. Please refer to the article by Mr Donnelly in Issue 58 of AMNET News (Spring 2014) for more details of this device. Follow-up care and rehabilitation is given through the Emmeline centre at Addenbrooke's, which is only accessed by referral from GPs, audiologists or other ENT surgeons.

For those who may consider this option, it is possible to trial the device beforehand to see what the sound quality will be like. Any patient who has been discharged from follow-up can be referred back for an assessment through their GP.

As you will have seen from a number of previous member articles, the personal experience of wearing a cross-aid hearing device will be unique to each of us. With patience, persistence and a period of adjustment and by working with the audiologist who is working to enable the highest quality of sound perception for us, many benefits can be gained to improve quality of life, but *this is a period of rehabilitation and not an instant process.* Sound that is transferred via the cross-aid will not be exactly like the sound perceived through your ear before it was deaf, but through persistence in using the device, you can allow your brain to adjust to slightly different sounds – for me this has improved my sense of balance, helps to mask the tinnitus from the deaf ear, helps with the location of sound, helps when driving (as I am deaf on the left side) and stops me jumping out of my skin when my husband appears in the room.

Rehabilitation after fitting of the BAHA will be done through the Emmeline centre, as this requires specialist rehabilitation from the experienced team there. As sound is transmitted through the bones of the skull, the brain will need to adjust to differently perceived sounds. Feedback from patients who have undergone this procedure has been very positive.

Facial Nerve Service – Addenbrooke's will be submitting a business case to the Cambridge GP Commissioning Group to develop the current Facial Palsy Clinic, run by Mr Price, into a Facial Palsy Service. Currently there is no facial physiotherapy offered.

The proposed service would include:

- Plastic Surgery
- Ophthalmology
- ENT
- Facial Physiotherapy
- Speech and Language Therapy
- Clinical Psychology

If the submission is successful it would complement the other services offered within the skull base unit. It is expected that the team will hear about the outcome of this submission by this time next year.

Mr Tysome then answered many questions from members present at the meeting, both from the floor and more personally at the end of the meeting.

[Two members have since commented that although they could hear and appreciate the presentation by Mr Tysome, they were unable to hear the questions that were asked by members. If you feel you have any comments on how we can improve this situation in future meetings, do please let us know. It is our intention to ask our speaker to repeat questions from the floor in future, so that we can all hear and appreciate the meaning of the questions. *Ed*].

My SSD Hearing Improvement By David Brown

Whilst it is our policy within AMNET as a charity not to endorse proprietary products, we feel that the following article by our member, David Brown, may well be of interest to many in enhancing hearing in social situations.

I had surgery for an Acoustic Neuroma at Addenbrookes in 1995. I had no useful hearing in my right ear and no hearing in it at all after surgery. Fortunately, I also had no tinnitus. I was issued with a wireless cross hearing aid as was available at that time, but found it of limited use since it amplified all sounds equally so that speech could get drowned by background noises. In 2013 the hospital replaced my hearing aids with modern digital *Phonak* hearing aids, and while this proved a significant improvement, I realised that modern technology could be used to improve hearing even further.

I needed something which was compatible with my NHS issued *Phonak* hearing aids, and didn't want to use a loop-based interface since I had no experience

of using loops, and it seemed to introduce an intermediate technology between the external hearing device and my hearing aids.

On searching the internet, I found an established range of equipment from *Phonak*, hence compatible with my hearing aids, under the name Smartlink+. They were also, at that time, just introducing a second generation of this equipment to serve the same purpose under the '*Roger*' brand name. None of this equipment was available on the NHS, and since this was likely to involve a reasonable personal expense, I wanted to be sure that it would be really beneficial. Fortunately, Addenbrookes did, however, have Smartlink equipment (a version called Zoomlink+) available for loan which I could try.

The key features of both these products, Zoomlink+ and Roger, are very similar, and for me they provided improved hearing capabilities in noisy environments or open spaces. They consist of a sophisticated microphone/transmitter unit which can be placed in a suitable position on a table, worn round the neck or hand-held, and a receiver attached to the hearing aid.

The microphone can be switched between:

- '**Super Zoom**' mode - when you can point it towards the person you wish to hear
- '**Zoom**' mode - when it will pick up a wider sound source – perhaps a group of 2 to 3 people
- '**Omni-directional**' mode - when it will pick up sounds all around the microphone. It is also designed to reduce background noises.

The Smartlink+ uses FM radio transmission to communicate with the receiver while the Roger system uses a digital transmission, less prone to interference. When in use, either equipment switches off the hearing aid microphones (both ears) so only the equipment input is heard, plus any natural hearing which you may have.



David Brown is dining out here - the Roger Pen on the table in front of him.

The key component of the second generation Roger

system for SSD users is the Roger pen, which has similar capabilities to the Smartlink+, but while the Smartlink+ is a neat black box-shaped device, the 'pen' is a smaller pen-sized device. It can automatically switch between Super Zoom and Omni-directional, based on its position, or it can be manually set to the desired characteristics.

I had the use of a Smartlink+ system from Addenbrookes for a trial period of 2 weeks. My hearing aids had to be programmed to support the system, done for me at the hospital, and this programming also allowed me to try the Roger pen system at a later date. I was sufficiently impressed by the Smartlink+ system that I bought a Roger pen system, which was offered under a 21-day money-back system, to try as well. The cost of both systems is almost identical, at very approximately £750 in my case.

The Roger pen is, as its name implies, pen-sized and shaped and can easily be mistaken for a pen. It is therefore fairly discreet and may not be noticed. I found the control buttons are quite small and it took me a little while to become accustomed to them. It is powered by self-contained rechargeable batteries but it has no indicator to tell when the battery power is getting low. I understand a full charge should last around 6 hours but I believe it would be advisable to charge it up regularly after use. The Roger pen also has bluetooth connectivity suitable for a mobile phone, but I have not tried that.

This photograph shows my hearing aids and the Roger Pen. The battery box for one aid is shown and was removed to fit the Roger Receiver to the aid.



Testing to find if it was beneficial had to be practical and subjective.

Did I find the equipment helpful? I regularly meet with a group of friends so I used it

when we socialised at a local sports centre and had pub lunches. I found I could now hear conversations clearly. There was still some background sound but the sound quality of speech was so clear that I could reduce the volume on my hearing aids, which reduced the background sound even further and helped voices to be heard more clearly. I found the volume control on my hearing aids very valuable for this purpose in all environments.

Many restaurants nowadays can be very noisy due to lack of sound deadening décor or background music. It was much easier again to hear and join in conversations. It could still be difficult to hear in extremely noisy environments, but the equipment does still help and my 'normal hearing' friends assure me it is difficult for them to hear in these environments too.

When walking in the open air or shopping in supermarkets, voices which were previously difficult to hear could be heard much more clearly - provided the microphone was directed in the general direction of the speaker. However, I found I need to be willing to point the device in the appropriate direction to get the greatest benefit. Fortunately, it does not need to be thrust into anyone's face and can be used fairly discreetly.

When travelling in the back of a car, it is often difficult to hear what front seat passengers are saying, even for people with normal hearing. By putting the microphone between the front seats, everything can be heard, probably better than for those without hearing difficulties. It also helps when travelling by train. I had never had much difficulty hearing in a domestic or small office environment where there was negligible background noise and generally only one person was speaking at a time. The system therefore offered little or no improvement in this environment.

The fact that the Roger system is smaller and more discreet than the Zoomlink+ does lead to the risk of it being forgotten and left lying on a dining table or even lost, and I've found care needs to be taken with it in this respect. The pen can be easily worn on a cord around the neck. This made it easier to hear my own voice – not quite the objective but I find that it is a convenient way to carry under clothing. I would not generally like to ask someone to

wear it so that I could hear them more clearly but this could be useful in certain situations. By accident, I found that if I left the Roger pen lying on a table and temporarily left the table, I could still hear conversations some distance away!

It can be connected to the earphone socket of an audio device (e.g. television) and the sound is transmitted through my hearing aid with no delay so that speech is synchronised with the presenter's or actor's lips – sometimes a problem with some technology. This is a boon in some situations. I enjoy Formula 1 motor sport programmes which tend to be loud and noisy. Using the Roger Pen, I can mute the TV Sound but still hear it via the headphone connection. (This requires that the television allows this set-up).

I've found that hearing aid batteries need to be replaced more frequently, since they also provide power to the receiver which is attached to the hearing aid.

In summary, I am very satisfied with the Roger pen. Having had it for almost a year, now, I am still delighted with it. It cannot work miracles in all sound situations but it is a vast improvement in most situations. However, in view of the cost involved, if anyone is interested in it, I would recommend finding a source which allows the system to be tried in your environment to ensure it is beneficial to your lifestyle before being committed to the full expenditure. Personally, having got used to it, I would not be without it.

[Many thanks David for this very interesting article which could well help many readers who experience similar limitations with their hearing in social situations. If you have experience of any other devices or helpful suggestions to make that may benefit our readers, do please contact us. *Ed.*]

REAL EAR MEASUREMENTS

By David Brown

"Real Ear Measurements" appears to me to be a major step forward in enabling hearing aids to be suitably set up for a given person's requirements. I have recently encountered it being used by some audiology departments over the last year or so but

so far as I can tell, it is not by any means common to all.

Whereas previously patients were asked whether or not variations in the hearing aid set-up seemed to be better or worse, the “Real Ear” procedure provides a more scientific assessment using a wide range of sounds to provide the “ideal” set-up for the patient, thereby removing the subjective element. The “Real Ear” procedure with me consisted of placing tiny tubes to measure the sound level in the ear canal and playing a wide range of scientifically selected sounds, made up primarily of words from different languages and dialects from around the world, to give a thorough sample of the sounds a human ear needs to hear and these are analysed to determine the sounds reaching the patient’s ear drum. These are compared to a prescription, calculated from the hearing test, and the patient’s hearing aids are then set up to provide the optimum sound for the patient. This removes the subjective question from the audiologist to the patient – “Does that sound better?” – although the audiologist does check that the patient is happy with the settings. I believe the procedure may vary slightly between practitioners but the general result is the same.

I found that my digital hearing aids, set up using Real Ear Measurements at Addenbrookes, provided a vastly improved quality of hearing and the clarity of sound from my deaf side in particular was greatly enhanced.

As an aside, my wife, Carol, who suffers from Sensory Neural Deafness, when she heard of this procedure, approached her own audiology department in a major London hospital to enquire about the availability of the procedure. She found it was just being introduced and so she was included in their programme. She had always felt that her hearing aids were not as good as they should be. Suffice it to say that while she kept asking me to turn up the television volume previously, she now keeps asking me to turn it down!

Therefore I believe it is worthwhile ensuring that you get access to an Audiology specialist who can provide programmable hearing aids and Real Ear Measurement services.

DVLA and Acoustic Neuroma Guidance provided by BANA



Are you approaching your 70th Birthday?

One of our members, Peter Otley, experienced a few problems when renewing his driving licence at age 70. This led to a delay of three months in receiving his renewal. As he needed to renew his driving licence again, he contacted us at AMNET about this as he realized it was likely to be a problem for other members too. I approached Alison Frank, our Chairman and Debra Nash, CEO of BANA, to see if there was any definitive guidance about this. We received the following reply from Debra Nash:

“I can confirm I have received a definitive reply (after quite some battle), which is on our website and was noted through our social media at the time.

Please see link below:

<http://www.bana-uk.com/dvla-and-acoustic-neuroma-guidance/>

Hope this helps”.

For those without a computer, the information contained on the BANA website when you click on this link is as follows:

“The issue of driving and declaring an acoustic neuroma is a dilemma for many patients. The DVLA has issued their own guidance for medical conditions, which includes acoustic neuromas on page 16. Further, a number of members have queried how to complete driving licence applications at age 70 and thereafter, **with regards the question relating to having a ‘brain tumour’ BANA has raised this question directly with the DVLA and the guidance below includes their Medical Advisor’s response** - [please see next page]

DVLA and Acoustic Neuroma Guidance provided by BANA

Group 1 licence holders ‘can tick **NO** to the question concerning a brain tumour. However, if they are suffering from sudden and disabling giddiness, they need to notify us [DVLA] separately about this condition.

For Group 2 (LGV/PCV) drivers, DVLA do not need to know about an acoustic neuroma unless it is accompanied by disabling giddiness and/or the condition is bilateral’.

Having received this information I contacted the Nurse Practitioners at Clinic 10, Addenbrooke’s Hospital in case they were unaware of this guidance. They asked that:

any patient with *sudden onset of giddiness* should contact them at Clinic 10 for advice - contact details are as follows –

Juliette Durie-Gair and Nicola Folland,
(Skull Base Nurse Practitioners):
Tel: 01223 348672.

We are in the process of upgrading our website and will ensure that information about the renewal of driving licences is available there as soon as possible.

Many thanks to Peter Otley for raising this relevant issue. We hope your driving licence renewal was much more straightforward this time. [Ed.]

Department Of Transport – Am I Fit to Drive?

A new drug driving law came into force on 2nd March 2015.

Having looked at the document on the Department of Transport website it seemed relevant to relay key information here which may be relevant to you.

KEY MESSAGES FOR PATIENTS

- Certain medicines may affect your ability to drive.
- It will remain an offence to drive while your ability is impaired by drugs and, if in doubt, you should not drive.
- A new offence of driving with certain controlled drugs, including some prescription drugs and a number of over the counter medicines, above specified limits will come into force on 2 March 2015.
- The new law provides a medical defence if your ability to drive is not impaired and you are taking a medicine in accordance with the advice of a healthcare professional and/or the information in accompanying patient information leaflet.
- Ask a member of the pharmacy team or your doctor (GP) for more information.
- Always follow the advice of a healthcare professional and read the accompanying leaflet when you take your medicine.
- New information is starting to appear on the label and in the accompanying patient information leaflet of those medicines covered in the new regulations and for other similar medicines which may also be picked up in testing for the new offence.

Additionally the document states that “patients who take legitimately supplied medicines should keep evidence with them to speed up investigation into the medical defence and reduce the inconvenience to the patient in case the police stop them”. If you take medications on a regular basis you may like to know that: “following advice from a panel of medical and scientific experts, the 8 drugs most associated with medical uses included in the new offence and set at a level where road safety risk arises are:

Clonazepam, Diazepam, Flunitrazepam, Oxazepam, Temazepam, Methadone, Morphine and Amphetamine and other substances like selegiline which can metabolise into amphetamine and are sometimes used for medicinal purposes.

Editorial



Hearing loss in the workplace

By Samuel Trychin, PhD, listed in the National Register of Health Service Psychologists.

Please make every effort to attend our AGM this year as we need your input within AMNET to continue as a local charity. The only alternative may be to become an East Anglian Branch of BANA. It is therefore doubly important to attend this meeting as it will be followed by a presentation by Debra Nash, CEO of BANA, where you will be able to hear what being part of BANA may mean for you. There is no coincidence that Debra will be speaking at this meeting, following our announcement of our recognition that we need to make changes.

It was Alison Frank, our current Chairman, who was responsible for the setting up AMNET to support patients and their families as they go through the traumatic situation of diagnosis and treatment of acoustic neuromas and meningiomas based at Addenbrooke's Hospital, Cambridge. From those early days Alison has been inspirational in her desire to help and support others going through the same journey as she was – a journey she hoped that no one person would have to do alone, without the back up of others to talk to, especially from those who had experience of what it felt like to deal with a diagnosis of one of these rare skull base tumours. She was soon joined by Chris Richards (and others), and the two of them have worked tirelessly over the last 19 years to develop AMNET into the self-help charity we all benefit from today. It is a real credit to Alison and Chris to have done this, especially in the early days when they too were going through treatment and had busy lives and young families. This has now grown into a network that extends beyond the East of England – partly due to the reputation of Clinic 10, which means that patients choose to come to Addenbrooke's for their treatment, and over time, many of our members have moved to other parts of the country, but continue to support us.

I am sure you will join me, and the AMNET Committee in extending our thanks and gratitude to Alison and Chris for all their endeavours, given freely over the years. Alison wishes to remain as the point of contact for AMNET and to continue to be a trustee and active member of the Committee, but would like to step down from being Chairman.

Sally Hardy, Editor

This interesting article appeared in *ENT & Audiology News*, Vol 24, No 1, March/April 2015, and is written by Samuel Trychin, who was working as a control operator in the US Air Force when his hearing loss was diagnosed, and found that he was reassigned to a job in supply.

The issue of the onset pattern of hearing loss is discussed and this is an issue relevant to most of us with skull base tumours. For some the hearing loss may have been a gradual one over a period of years and we may have adapted to each small increment of hearing loss and failed to recognise its contribution to decreased job performance or impaired relationships in the workplace. This rang a bell for me, as I had been working as a Practice Nurse in a GP Surgery, and it wasn't until I acknowledged that it was me and not the stethoscope that was at fault, did I finally visit my own GP to have my hearing examined. The sudden onset of hearing loss, albeit single-sided, as will be experienced by those undergoing VS surgery, can potentially bring with it psychological and emotional effects like anxiety and/or depression, which Samuel Trychin acknowledges needs to be managed along with treating and accommodating the hearing loss itself. This may be a consequence of communication difficulties relating to hearing loss and show itself in bad habits such as bluffing or actively avoiding communication situations. He says that bringing such issues to the individual's attention in order to establish more effective communication behaviour usually requires information and perhaps some training.

Assessing the benefits gained from using hearing aids and assistive listening devices (ALDs) in employment situations is important in regard to the specific tasks a person who has hearing loss is required to comfortably and efficiently perform.

On 12th March 2015, Mark Harper MP, Minister for Disabled People, announced a limit of £40,800 per person/per year on the Access to Work scheme which will come into effect from October 2015. As this factor may affect some readers I would like to discuss this further in the next Newsletter along with further reference to the above article.

The Acoustic Neuroma and Meningioma Network (AMNET) Charity Number:
1073908

AMNET AGM

Notice is given of the Annual General Meeting (AGM) of AMNET to be held at Addenbrooke's Hospital on Saturday 11th July, 2015, at 12.45 hours. **The meeting will be preceded by a light lunch which will be provided for you and available from 12.00 noon. Please let us know if you have any special dietary requirements.**

The minutes for the last AGM appeared in the AMNET Newsletter following that AGM (Autumn 2014). The accounts for the last financial year are included with this notice. The full auditor's report will be available at the meeting or on request.

Please make every effort to attend the AGM. If you are unable to attend then a proxy form is included with this notice.

AGENDA

Apologies

Minutes of the last meeting

Chairman's Report

Treasurer's report and accounts for last year.

Election of Trustees

The following trustees are prepared to stand again:

Alison Frank (but no longer as Chairman)

Carol Clothier

Sally Hardy

Mick Clothier

Bronwyn Lummis

Charlie Lummis

Heidi Pratchett

Any other business which may be transacted at an AGM

If a member wishes to ask a question this must be submitted in writing to the Secretary, at the address, given below, to *arrive* a minimum of seven days before the AGM.

By order of the Executive Committee

Heidi Pratchett
Secretary

Dated 26th May 2015

C/o The Old School House
The Green,
Old Buckenham
Norfolk
NR17 1RR

Accounts

AMNET Accounts 2014 and 2015

	Year End 31 Jan 15	Year End 31 Jan 14
Income	£	£
Subscriptions	1700.0 0	1640.00
Donations	1446.0 0	477.00
Booklet Sales	23.00	21.00
Fundraising	123.00	265.20
Trophic Simulators-recycle	50.00	
Bank Interest	0.17	0.21
	3342.1 7	2403.41
Bank Account		
Brought forward	5596.2 9	5393.11
Carried forward	6967.9 0	5596.29

	Year End 31 Jan 15	Year End 31 Jan 14
Expenditure	£	£
Printing	1097.25	
Postage	472.75	610.14
Booklets/BANA	106.05	75.50
Website (Domain name)	30.00	30.00
Miscellaneous	264.51	96.74
	1970.56	2200.23
Surplus for year	1371.61	203.18

AMNET AGM: Proxy Form

To: The Secretary
C/o The Old School House
The Green,
Old Buckenham
Norfolk
NR17 1RR

(Please tick boxes as applicable. Leave blank those that do not apply)

I will be unable to attend the Annual General Meeting.

I wish to give my discretionary proxy to the current Chairman (Alison Frank)

I wish to give my discretionary proxy to
(insert name) who will attend the meeting

I confirm I am a member of AMNET.

Signed..... Name (Please Print).....

Forthcoming Meetings - Our Autumn Meeting will be on **Saturday 21st November, 2015** in the **Boardroom at Addenbrooke's Hospital**. Speakers on that occasion will be **Frances Dewhurst** from **Cambridgeshire Hearing Help** and **Joy Badcock, Lipreading Teacher** from **Addenbrooke's Hospital**. Further details in our next Newsletter.

Directory

AMNET

W. www.amnet-charity.org.uk

E. 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

E. admin@bana-uk.com

T. 01246 550011

Freephone. 0800 6523143

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

Meningioma UK

W. www.meningiomauk.org

E. support-enquiries@meningioma.uk

(Patient information & support)

meningioma@ellapybus.greenbee.net

(Meningioma UK)

T. 01787 374084

The Brain Tumour Charity

W. 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

E. informationline@hearingloss.org.uk

T. 0808 808 0123 (Info line - Freephone)

Textline. 0808 808 9000

British Tinnitus Association

W. www.tinnitus.org.uk

E. 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 (CAMTAD)

www.cambridgeshirehearinghelp.org.uk

E. 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

E. info@changingfaces.org.uk

T. 0845 4500 275

Facial Palsy UK

W. www.facialpalsy.org.uk

E. 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

Addenbrookes Hospital

Neurotology & Skull Base Surgery Unit

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

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.

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 If you would like to make a contribution please telephone or email me.