

# AMNET NEWS



## Issue 61 Spring 2015

**Happy New Year** to all our readers. The whole Committee within AMNET hope that you are well and enjoying the first signs of Spring in 2015. We were very pleased to have a large turnout to our Autumn/Christmas meeting on November 22<sup>nd</sup>, where we had a delicious festive lunch. Thank you for your contribution to this shared event.

Did you manage to park in the Hospital Car Park Number 1 and use your ticket (validated by Alison Frank) to obtain reduced priced parking? We need to hear back from you if you experienced any difficulties with this. As this is a new arrangement, I will again detail what to do about car parking at Addenbrooke's Hospital for those attending AMNET Meetings.



- **Park only in CAR PARK 1**
- Take a ticket at entry and take the ticket to the meeting with you.
- One of the committee members needs to sign and print "AMNET" on the ticket.
- Present to the customer service desk in the car park, adjacent to the exit barriers before payment to obtain a validated ticket.
- Pay £3.40 in the pay station before leaving.
- Use the paid ticket to exit.

Without the appropriate information written on the ticket I am afraid the validation would be refused.

## Our Autumn/ Christmas Meeting

was held in the Boardroom at Addenbrooke's Hospital, Cambridge on Saturday 22<sup>nd</sup> November 2014, and featured a presentation by **Kate Burton**, Consultant Radiographer in Neuro-Oncology at Addenbrooke's.

We were delighted to welcome back Kate Burton to speak to us for our Autumn Meeting. This was a very well attended meeting, which probably reflects the very high respect that our members have for the outstanding support that Kate gives to our members.



Kate Burton

Kate began her talk by giving a little background about herself. She has been qualified for 20 years now and specialized initially in neurology and in the treatment of malignant tumours. She now concentrates on the treatment of vestibular schwannoma (VS) tumours. Kate outlined that her talk would update us on what has changed in the last 10 years – how Clinic 10 at Addenbrooke's Hospital is now formally a Skull-based Clinic. This would be followed by an outline of what radiotherapy is and how it is delivered – the technology involved.

**Our Next Meeting** - Will be on **Saturday 18th April, 2015** in the Boardroom at Addenbrooke's Hospital, Cambridge. On this occasion, we are pleased to welcome **Mr James Tysome, MA, PhD, FRCS (ORL-HNS)**, Consultant Skull Base and Hearing Implant Surgeon and Clinical Lead of the Skull Base Team at Addenbrooke's Hospital, Cambridge. Doors will open at 13.00 and we expect the talk by Mr Tysome to start at 13.30 - Alison

## **Teamwork**

Kate stressed her firm belief that communication and discussion = good outcomes and how it is most important that the patient is involved in this process. During the Skull-Base Multidisciplinary Meeting (MDT), multidisciplinary professionals meet to review MRI scans to determine tumour type and discuss treatment options before seeing patients in clinic later that day. These meetings are held twice per month, on the 2<sup>nd</sup> and 4<sup>th</sup> Friday of the month. The team present at the MDT meeting will include ENT consultants, neurosurgeons, oncologists, radiologists, radiographers, plastic surgeons, audiometrists and nurse practitioners. During a typical meeting the team will talk about new patient referrals, which now involves referrals from the whole area served by Addenbrooke's Hospital and from further afield, including from London to the Midlands. The relevant hospitals can join up by video link to enable consultants to discuss MRI scan images for new patients. At this meeting there will also be discussion about patients who have had surgery; watch, wait and re-scan patients where growth has been seen and those with tumour growth post radiotherapy. The MRI scans will be reviewed and patient symptoms discussed (if known). There will be a review of the pathology for each patient and a review of any radiology given.

The MDT Skull-Base Meeting is then followed by a clinic where all the disciplines/professions involved in the MDT Meeting are available for consultation with patients within a single clinic visit. This has led to an improvement in the patient experience and the service provided. Informed patient choice for new patients given the diagnosis of a vestibular schwannoma tumour is vital, and the presence of multidisciplinary specialists enables the patient to have access to more than one specialist on that occasion and between specialists, if necessary, without having to make repeated visits to the hospital.

Data collection about patient treatment options, patient choice and patient outcomes following treatment for vestibular schwannoma is now centralized for units from around the UK on a National Vestibular Schwannoma Database. Data is entered on a voluntary basis 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 on-going process and results

from data collection are yet not currently available to the general public.

Patients attending the MDT Clinic complete a quality of life questionnaire which is vital in taking the patient viewpoint into account. The aim of the Skull-base Unit is very much to look forward with research, to offer patients choice with information and support in making that choice.

Kate commented that by 2002 patients were finding information about treatment for vestibular schwannomas on the internet and then attending clinic and proactively asking for a particular type of treatment. [*Obviously we should all be wary of information on the internet – the internet is not regulated and can lead to anxiety and misinformation, Ed.*].

There was a brief discussion about treatment options for VS, including the surgical option, watch wait and re-scan and radiotherapy. The size and location of the tumour may make one treatment option more appropriate, but this will be discussed with the patient when their diagnosis is given and following on from the MDT meeting.

## **Radiotherapy as a Treatment Option for Vestibular Schwannoma (VS) Tumours.**

For those receiving radiotherapy as a treatment option for their VS tumour, the treatment will be given using a form of radiation. This has historically been used as a treatment for cancer, but can be used successfully in non-cancerous tumours too. Treatment is targeted at tumour cells to damage the DNA coding in the genetic material and thus stop tumour growth. A careful balance is made by the oncologist (the doctor who plans and delivers the radiotherapy) between healthy and tumour tissue. The advancement in medical imaging has improved the ability to lower the dose to normal brain surrounding the tumour by allowing the practitioner to see the targeted area more clearly. The aim of this type of treatment is to stop the tumour growing, but will not remove it. Careful follow-up by MRI scanning is necessary after treatment.

Radiotherapy encompasses many different forms of treatment that use ionising radiation. Radiotherapy can be given as radiosurgery – this is a single treatment, **OR** by a number of treatments – this latter

delivery is called fractionated, and usually involves a plan of 30 treatments.

Radiosurgery started with **Gamma-knife**, which was developed in 1968 in Sweden. This involves no knives, but is a single treatment and has been used for brain lesions and conditions since that time. This is a very expensive treatment as the machine uses 201 radioactive isotope sources (Cobalt 60 Gamma Rays). The gamma rays combine to form a high-energy point at the focus, with each ray being too individually weak to damage the healthy brain tissue in its path or surrounding areas. The source of the isotopes in this machine needs replacing every 7-10 years and as the machine ages, the treatment will take longer as the radioactive source deteriorates over time. Gamma-knife surgery is now available in London, Sheffield, Leeds and Bristol. The treatment requires fixed head frame immobilization. Planning and treatment are given in the same day, but sometimes an overnight stay might be necessary.

**Linear Accelerators (Linacs)** can also perform radiosurgery. They utilise dedicated SRS platinum software and hardware (stereotactic) to deliver small highly targeted x-ray beams that allow the radiotherapy to be delivered as a single dose. This technology and machinery can also allow the radiotherapy to be delivered over a number of treatments (or fractions) called fractionated. The word stereotactic means locating a site using three-dimensional coordinates. Fractionated radiotherapy may be favoured for larger VS tumours where the lesion has already started to press against the brainstem. Enhanced medical imaging is used for guidance and the delivery of treatment to ensure correct positioning. Increased toxicity is a possibility in the treatment of larger tumours which might affect balance. Fractionating the radiotherapy may minimise the side effects the patient experiences during treatment and in the immediate months following treatment. This form of radiotherapy is widely available, and requires the patient to be in the same position every day. Many centres, including Addenbrooke's Hospital, use a frame comprising an individually made mouth plate and back plate for each patient, which will ensure that the patient is in the same position each day and also remains still during treatment. A mask system is also possible.

**Cyberknife (Linacs)** operate by use of a robotic arm design, which can deliver around 150-200 beams, each sent from a different unique angle, pin-

pointed to the tumour site. Each pencil thin beam used is continually tracked and imaged to ensure treatment location. The Cyberknife is a type of linear accelerator and has been designed specifically for radiosurgery. This form of radiotherapy is generally given over 3 treatments. The patient will be monitored over the following 20-30 months to evaluate hearing preservation, as this form of treatment may be preferable (compared to the single treatment option) for those where hearing preservation is a possibility, due to the location and size of their VS. Patients treated with the Cyberknife system will wear plastic masks and the machine adapts to compensate for small movements in patient position during treatment. This treatment is still new, and the available evidence-base relating to patient outcomes is currently small.

**Proton Therapy** uses particle beams, which have a cut-off point at the point of treatment. This form of treatment is currently used for children, or adult brain tumours where a higher dose of radiotherapy is required to treat the tumour. This type of machine is not available in the UK yet, but has been reported in the news recently, when used in Switzerland. There is a national NHS referral process in place for treatment in the USA, but the UK is due to have two centres open by 2018.

### **Patient Choice**

Radiotherapy treatment for VS tumours is not appropriate for randomisation trials. Data input from single-centre treatments and follow-up can be poor and widely variable in how outcomes are measured, reported and assessed. Within Addenbrooke's Hospital, tumours are now measured in 3D by a specialist radiologist and measurement of the VS tumour involves tumour that is visible outside the intracranial area. Patients with tumour present only within the intracranial area are usually referred for watch, wait and re-scan. Radiotherapy is an option for small to medium size VS tumours. There are very good control rates for this form of treatment.

### **What happens to the tumour after radiotherapy.**

The VS tumour may appear slightly bigger after treatment and some symptoms can increase until the tumour shrinks. The middle of the tumour may appear dark on an MRI scan - this is where the centre of the tumour has been destroyed. There are mini-

mal short and long-term side effects due to toxicity. By combining beams or channels of beam, the focus can be built up on the targeted area, so only low dose radiology is administered to normal tissue. There is only a small chance ( $\leq$  one percent for every decade of life following treatment) that the radiotherapy may cause another tumour to form in the area where the treatment has been delivered and 50% of these may be a malignant brain tumour. This is a very low risk, but it is important to consider in younger patients, and particularly in children.

### Summary

Radiotherapy is an effective treatment and an alternative to surgery for patients with a small to medium sized VS, and has minimal short and long-term risks. It can be delivered as either a single dose (radiosurgery) or over a number of treatments (fractionated). A range of technology is available to deliver each of these options.

[*Kate Burton has checked and verified the information given here and in her correspondence with me said that the main message that she wished to convey to members was that:*

“It is important for the patient **to consider radiotherapy as either a single or fractionated treatment** and not get caught up in the industry/mannufacturer’s advertising of gamma/cyber/Linac etc

– all the machinery can offer both options (although gamma knife tends only to be one treatment)”.

Alison Frank thanked Kate Burton for her valuable contribution and this was followed by a short question and answer session.

## An Uplifting Quotation

**Some people grin and bear it; others smile and change it.**

This frequently cited approach to work and life has been seen in print since 1945 and is of unknown authorship. My husband saw this recently as inspiration for children in a school he was visiting as a School Governor. *Ed.*

## AMNET MEMBER UPDATES AND CONTRIBUTIONS

*(Always so welcome and relevant to other members, so please do continue to contribute comments about your experiences and items that you think may be relevant to other members. This is one of our primary aims as a Charity, Ed).*

### Eyeing up the problem by our member Rachel Davies

Last year my eye became completely unmanageable. I went from using Celluvisc drops with Lacrilube ointment at night to endless tubes of Lacrilube, and yet my eye was permanently sore and often streaming.



In desperation I went to see the plastic eye surgeon who said that surgery would not help. He made some useful suggestions about wraparound sunglasses and changed the ointment to Simple Ointment.

I found the latter so stiff it was even more difficult to use and anyway my eye was no better. Then it occurred to me that I get hay fever in my eyes, (both eyes, obviously!), but had failed to find any drops that did much. I went back to my GP who said that hay fever tablets would be worth a try. So we tried the traditional Cetirizine at night and there was a dramatic improvement. I still need Lacrilube rather than drops, even during the day, which is a nuisance in terms of poor vision, but the soreness is now manageable.

I would therefore recommend considering other factors when dealing with sore eyes because infections, allergies, ulcers and so on can add to the problem of the eye not closing and blinking properly.

[*Many thanks Rachel for this very helpful article, which may well be a familiar experience for other members. A very wise recommendation. Ed.*]

## Recent Balance Issues by our member Peter Whalley



Hello, I have had a recent experience involving balance issues and wonder whether other AMNET members would find this information useful.

I had an acoustic neuroma successfully removed by Mr Moffat in December 1997. I am now, not quite, at state pension age but getting close.

Since 1997 I have been unconstrained by balance issues, just more careful in how I go about activities, for example when working with ladders and scaffolding on DIY projects. To my surprise, one unexpected improved skill was skiing, absent my innate balance system telling me to 'lean into the mountain' at every opportunity.

However, whenever walking together with other people I have tended to forge ahead alone, concentrating on keeping a steady course. I have become increasingly aware of this being associated with an inability to walk with others and to talk simultaneously without wavering in my path.

More recently I started to experience bouts of swollen/inflamed toe joints in one of my feet. I eventually consulted a podiatrist who immediately commented upon the way I was walking: that I was slightly leaning forward and walking with emphasis on big-toe contact with the ground. With temporary sole inserts to realign my foot-fall, I immediately noticed an improvement in steadiness. That was 5 months ago.

The inflammation of my toe joints quickly disappeared and has yet to reappear. I no longer use the sole inserts but continue to work on maintaining the corrected walking posture. I now go for walks with others at their pace whilst conversing and unconsciously maintaining a steady path.

My reason for reporting this is that I thought my balance issue with walking was an unavoidable consequence of my operation and, whilst not apparent over the first few years, was becoming more problematic with age. Now so simply, it seems the issue has been resolved, independent of its origin.

In the longer term, if I cannot maintain an appropriate foot-fall I will invest in custom made sole inserts, as recommended by the podiatrist.

Regards,  
Peter Whalley, 31st January 2015.

*[Thank you Peter. This may ring a bell for others, especially if it is a longer-term symptom. I asked Peter if he had been skiing this year and whether he noticed any differences. He answered: "sadly no skiing this year or in recent years - no offspring or other 'hooligans' available to keep an eye on my antics! That's my excuse anyway." Ed.]*

## An update on my progress to recovery by Peter Lawrence

I was operated on for a vestibular schwannoma in 2011 and so far MRIs show that it was successfully removed. I am totally deaf on my right hand side.

My experience prior to the operation, which include a failed gamma knife treatment, are described in my previous articles for AMNET (see Issue 39 - Spring 2007; Issue 44 - Autumn 2008; Issue 51 - Autumn 2011; Issue 57 - Autumn 2013), and here I discuss my single-sided deafness (SSD) and attempts to deal with it.

Before my operation, Mr Moffat told me that as my hearing on my right side was already distorted, I wouldn't notice the complete loss of it. However, this was not the case, as even poor hearing can help one locate the source of sound. And, as so clearly described by Brian Moore in his article in AMNET ( Issue 59 - Summer 2014), we need to locate the source of sound to help us distinguish signal from noise – particularly important for speech discrimination. I have found SSD to be a serious handicap that one should be prepared for.

The approach to SSD depends quite a bit on the hearing one has on the good side. I have good quality hearing, but with some loss of high frequency (presbycusis), that is very common in older people (I am now 73). The kind and clever audiologists in Addenbrooke's, particularly Rachel Knappett, have worked hard to help me, and I have made extensive and careful trials of two different kinds of hearing aids over the past 3 years. My CROS hearing aids, in addition to amplifying the high frequency signal received on the good side, take the sound from the deaf side and pass it - either via a wire, or by wireless signal - to the good side.

I have tried hard to be objective and compared my ability to understand what people are saying in a noisy party, or at a small dinner party, or in the theatre, and have regretfully concluded these hearing aids have not usefully improved my speech discrimination in these particular situations, and they can even make it worse. The primary reason is quite simple; the speech one is listening to is received in a background of distracting noise and echoes, and, as Brian Moore explained, someone with SSD finds it hard or impossible to separate signal from noise in these situations. The CROS hearing aid adds more input to the good side, and in noisy situations this can make things even noisier. Brian Moore had a vestibular schwannoma removed and uses only one hearing aid, but he needs to improve the hearing on his good side.

An additional problem with these aids is that batteries are needed on both sides and, particularly on the deaf side, they don't last long.

What to do? I do use my hand cupped around my good ear to cut out sound from some directions, and this can help. And of course, I turn my head to someone on my deaf side. If I do that, and then I cup my hand around my ear to reduce sounds coming from behind, the person I want to hear may respond by shouting, and this is usually a shock as it is so loud! For me the volume is not the problem, it is the conflicting sounds, but it is difficult to explain that to another person. Another problem is when one is, for example, listening to the radio. If another person speaks to you at a similar volume, (as the radio), the two sounds clash and turn each other into gobbledygook, and you understand neither. This is a real nuisance, as for the binaural person there

would be no such problem, and so they fail to understand what is happening.

One day I hope they will improve the aids. CROS – for example - if a pair of aids could work together to select the sound coming from one direction. Supposing I turned my head and looked directly at a person in a party, could the two aids amplify the sound coming from that person and reduce the sound coming from other directions? Our brain effectively does this by helping us attend to sound from a chosen direction. I expect the power to compute this might be too much for a little aid, but maybe not in the future. I wondered if it would help to carry a directional microphone that one pointed at the person one was listening to, this would be like a modern ear trumpet, and would certainly get attention, and make secret overhearing tricky!

I would be interested to know how many other people with SSD and reasonable quality hearing in their good ear, have found CROS aids really beneficial and why.

*[It would be interesting to hear your responses to Peter's question. I noticed in the Winter 2014 edition of Headline News by BANA, that David Brown (who had surgery at Addenbrooke's in 1995, gave an account of his experience with the Roger Pen which was compatible with his Phonak hearing aids and behaves like a directional microphone. He had use of a Smartlink+ system from Addenbrooke's for a trial period of 2 weeks. He had his hearing aids programmed to support the system and this allowed him to trial the Roger Pen system at a later date. As David is one of our members, he might like to consider writing about his experience with this device – which was good. Please note, however, that the Roger Pen is not available on the NHS scheme and would need to be purchased privately. Ed.]*

### **Can you help?**

It would be very interesting to hear from members how they cope with different situations. During meetings the following situations have been topics of conversation:

(See overleaf)

## Topics raised by members during AMNET Meetings

Are you able to offer any advice or experience at managing the following scenarios?

- How to manage a dry eye when swimming in a swimming pool or in the sea?
- How to locate a child/grandchild who needs help and is in a different room/part of the room, especially during the night?
- What does your deaf ear feel like during air travel post-surgery or radiotherapy?

If you are able to help, please contact me by e-mail/phone, see details on back page. Many thanks, Sally Hardy, Editor

## Captioned Performances at the Theatre

## Open air Shakespeare captioned performance

You may remember an article in our Spring Newsletter about how **Shakespeare at the George** were to arrange a captioned performance of their production *The Merchant of Venice* at the George Hotel in Huntingdon on Tuesday 1<sup>st</sup> July, 2014 at 7.30.

AMNET member Helen Bush and I went along to this performance, and well, it was an absolute treat! Helen took her husband and I took along a friend, and we booked for dinner at the George Hotel before the performance. We were both *very* impressed to have been notified (during the day of the performance) by a member of staff at the hotel that there was a serious delay on the A14 which was affecting access into Huntingdon. He suggested that we might like to travel earlier. This was very helpful, and something we both responded to with praise for that staff member the next day. The dinner was delightful and the play superb.

The hotel had suggested the best seats to sit in to get the optimal advantage from the captions - which were unobtrusive but at the same time clear and easy to read.

The performance was outside in their unique Jacobean courtyard and was complete with *real* accompanied bird song overhead! It must be an added incentive for actors to learn their lines accurately as they must know that the audience can see, word for word, what they should be saying.

This year the cast of Shakespeare at the George will be performing *The Merry Wives of Windsor* from 23rd June to 4th July. Tickets go on sale during March, 2015, so I am not sure yet when the captioned performance will be this year. I will update you in the next Newsletter. If you would like to have a look for yourself please go to:

[www.satg.org.uk](http://www.satg.org.uk) or telephone:  
01480 432444

It was interesting to read how Pam states in **BANA Forum** (*Headline News*, Autumn 2014) that if anyone goes to any concerts or shows in their area, it is always worth asking if they do discounted tickets for the disabled (hearing-impairment). She mentions that she has attended many concerts where the carer goes free of charge if accompanying a physically disabled person.

Check out:

[www.stagetext.org](http://www.stagetext.org)

for **theatres** listing captioned performances across the country

Also in the Forum, Judy talked of a great day out she had in London with discounted tickets for *War-horse*. She received an e-mail with a full synopsis of the play, including photos and a message hoping she would enjoy the play. At the theatre staff offered her the synopsis and/or headphones to anyone who wanted them. She reported that the caption screens on either side of the stage were not intrusive and that she enjoyed a wonderful performance.

For information about **theatre tickets** visit:

[www.nationaltheatre.org.uk/access](http://www.nationaltheatre.org.uk/access)

The discounted rate is also available to the person accompanying you.

So, what is stopping you? Do give a captioned performance a try – I certainly look forward to many wonderful days/evenings out enjoying entertainment where I can actually feel I have heard and understood the content and not missed bits. I am sure that Helen Bush and I will both go to the performance of *Merry Wives of Windsor*, and would welcome your company.

Sally Hardy

For information about **cinema performances**, the following contact details may be of interest.

Check out:

for **cinema** information, or for listings of 1,000/month subtitled screenings of **newly released films** try:

[www.yourlocalcinema.com](http://www.yourlocalcinema.com)

(where you will be able to click for SUBTITLED or Audio Described Cinema)

or call: 0845 056 9824 (24 hours, 7 days a week, local rate).

### Update on Disabled Person's Railcard

We have received the following advice from our member Janice Pettitt:

"If you have a hearing impairment and have a hearing aid all you need to do when you apply is send a copy of the first page of your battery book. I did this when I got mine (even though I never use the aid, I still have it). When I renewed it this year, online, I did not have to send any further copies. It just went through automatically.

I just thought that this might be of help in case some members were put off by telling social services."

Please refer to previous Newsletters for contact details of **Disabled Person's Card** and for **Disabled person's Railcard** (See Issues 57 and 60, which are available on-line if you no longer have your paper issue - [www.amnet-charity.org.uk](http://www.amnet-charity.org.uk)).

### Cambridgeshire Hearing Help Update

In their latest Newsletter, Cambridgeshire Hearing Help gave details of a merger between **Hinchingbrooke Audiology and ENT Departments**. The departments are merging at Hinchingbrooke Hospital and it is hoped this will provide greater cohesion for patients using those services. By combining expertise, they feel this has led to a larger more comfortable location and has also meant they have more space for specialist testing and the ability to expand as demand increases. For further information about this merger, please go to:

<http://www.hinchingbrooke.nhs.uk/page/our-services/audiology>

Cambridgeshire Hearing Help provide local access for hearing-aid users to attend for replacement batteries and re-tubing. Do look at their website (back page) for details of a service which might be local to you and save you a trip to Addenbrooke's for this reason. In their section under "**Audiology News**", they stress that "*if a client thinks any open fitting dome (from their hearing aid) may have come off in the ear, it is recommended that they see their GP (or if that is not possible, attend A&E).*"

### Dates for your diary

**Tuesday 10<sup>th</sup> March 2015 - Volunteer Training.** 9.30-12.30, twice a week, over 3 weeks. The March Community Centre, Station Road, March, PE15 8LE. Contact the office to book a place.

**Saturday 14<sup>th</sup> March 2015 "FANFARE for Spring"**, 7.30, presented by The Cambridge Concert Orchestra in aid of Cambridgeshire Hearing Help, at St. Luke's Church, Victoria Road, Cambridge. CB4 3DZ. Tickets £10 each. Discount for students and for groups of 4. Contact the office to book a place.

**Friday 20<sup>th</sup> March 2015 - Demonstration of Hearing Help Equipment** at Scotsdales Garden Centre. From 10.00-12.00 Drop-in anytime.

**Thursday 28<sup>th</sup> May 2015 - Demonstration of Hearing Help Equipment** at King Edwards Centre, Chatteris. From 10.00-12.00 Drop-in anytime.

**Friday 13<sup>th</sup> November 2015 - Demonstration of Hearing Help Equipment** at the Priory Centre, St. Neots. From 10.00-12.00 Drop-in anytime

## Recent Research Articles

### “Aberrant P13K/AKT/mTOR pathway found in vestibular schwannomas may be therapeutic target”

Peter Otlej noticed this article, which was published on the internet on 23<sup>rd</sup> September, 2014, and thought it might be of interest to readers. This is a small-scale and technical piece of research directed by Drs Gelareh Zadeh and Boris Krischek in the University of Toronto, which investigated gene expression in normal vestibular nerves and vestibular schwannomas.

[DOI: 10.3171/2014.6.JNS131433].

The article states that:

“gene expression is the process by which genetic information is copied (transcribed) from DNA to RNA and then translated into gene products (mainly proteins) in the cell. Although all genes in the makeup of a particular person are found in nearly all cells in the human body, gene expression varies. Genes may be turned off or they may be turned on at varying degrees. This determines the type of cell (for example, cardiac cells or skin cells) and the cell’s behaviour (normal or aberrant).”

A loss of function of a gene on Chromosome 22 has been postulated as a cause of VS and the team found that one particular signalling pathway that was consistently found to be overexpressed in VS cells was P13K/AKT/mTOR. The researchers claim that targeting this aberrant [faulty] pathway offers a potential for therapeutic treatment in the future for both VS and NF2. By using cells from an established schwannoma cell line, the researchers were able to test two compounds to the cell line which reduced tumour cell viability.

As this article looked interesting I approached the authors on behalf of AMNET, but did not receive a reply. I am therefore loath to attempt to interpret their findings here, but merely highlight this for readers to investigate further if interested.

Further information can be found on the internet at the following address:

<http://medicalxpress.com/news/2014-09-aberrant-pi3kaktmtor-pathway-vestibular-schwannomas.html>

There was an editorial about this article in the *Journal of Neurosurgery*, 121, No 6, pp 1432-1433, by Pier Paolo Peruzzi MD PhD and Russell R Lonser MD in December 2014, which was entitled: “Therapeutic targeting based on gene-expression profiling in vestibular schwannomas” [DOI: 10.3171/2014.2.JNS14321]. The editorial was very encouraging about the therapeutic target article and said:

“While additional work will be needed to attain a more complete understanding of VS biology that leads to new clinical treatments, the findings of the current study represent a critical step forward in understanding VS and developing targeted therapies. The authors should be commended for this important work. This study is further evidence that comparative gene-expression analysis has the potential to uncover information that will allow for a better understanding of tumour biology and tumorigenic pathway interactions. These findings will permit the formulation of new, targeted therapeutic strategies for treatment of VS. We look forward to further studies by this group and others (based on this work) into VS.”

It might just be a possibility that this line of research will shine the light on a future alternative treatment therapy for VS and NF2, and an area of clinical research that we will hear more about in the future.

In February 2015 the BBC1 programme *Panorama*, featured current clinical trial work being carried out at the **Royal Marsden Hospital** and **Institute of Cancer Research** in a programme entitled “**Can you cure my cancer?**” The use of the technique for targeting defective genes with drugs to treat patients with cancer, who had not been effectively treated by other means, was followed in a number of cases. You may find this programme interesting and informative. It was first shown on 11<sup>th</sup> February 2015 and will be available on IPlayer for the next 11 months.

[It was helpful to me in trying to understand the science in the therapeutic target article, Ed.].

## Recent Research Articles (continued)

### “Balance improved through hearing aid use”

Cambridgeshire Hearing Help mentioned this study in their latest Newsletter, and although it is a small study of only 14 elderly volunteers, the results were clinically significant and therefore warrant a larger clinical trial.

The researchers from the Washington University School of Medicine in St. Louis, Missouri aimed to see whether or not the posture and balance of the volunteers could be improved by wearing working hearing aids. They were aged between 65-91 years old with various levels of hearing loss. They found that when aids were worn and fully functional, participants maintained posture and balance better, especially under more challenging tests than when their hearing aids were switched off. According to Timothy E. Hullar, Professor of Otolaryngology (ENT):

“The participants appeared to be using the sound information coming through their hearing aids as auditory reference points or landmarks to help maintain balance.”

For more information, please go to:

<http://www.medicalnewstoday.com/articles/287180.php>

The team at Cambridgeshire Hearing Help feel that this is an excellent reason to make sure hearing aids are in working order and worn regularly as it could reduce the risk of injury caused by falls and maintain independence as long as possible.

## News from Action on Hearing Loss

To mark *Tinnitus Awareness Week*, which was from (2 – 8 February, 2015), Action on Hearing Loss announced a major investment to fund a new study at Newcastle University, which aims to accelerate the development of future tinnitus treatments.

The project will run for three years, cost £300,000, and will be led by Dr Mark Cunningham at Newcastle University. This project will involve researchers at Leicester University and the biotechnology company Autifony Therapeutics Ltd, who are currently conducting a clinical trial of a drug for tinnitus.

Lead researcher, Dr Mark Cunningham said: 'The focus of this project is to see if we can use electrical waves in one of the hearing centres of the brain to measure tinnitus both to discover if the therapy developed by Autifony is working and how it is having its effect. The use of an animal model of tinnitus will allow us to investigate brain wave activity in the hearing centres and develop a biological measure which can be used on patients in the clinic as well as future research.'

## EXPLORE MUSIC 01/2014

Alison Frank, our Chairman, has managed to locate a copy of this magazine, which is the first edition of EXPLORE MAGAZINE produced by MED-EL, a company that produce hearing implants. This new magazine has been set up with hearing at its heart and the topic covered in their first edition is **music**.

It is a fascinating read and covers many aspects of music, including its therapeutic use, acoustic design of a concert hall, the benefits of playing music to children, older people and those with psychiatric problems. At the end of this issue is a very interesting article entitled “Ten Second Glossary” which is all about “Binaural hearing” and discusses the difference between hearing with two ears and with one ear. The article very eloquently describes the problems of determining the location of a sound. Look out for the magazine at our next meeting, which is on display with other helpful leaflets and booklets.

## Helpful Hints

**Acoustics** – The “minimalist” option. Changing the décor in a room to include wooden or tiled floors, bare windows or blinds and other hard surfaces can make it *more* difficult to hear. Carpets and soft furnishings like curtains and tablecloths absorb echo and can make it easier to hear.  
*Sally Hardy*

## FUNDRAISING



We reported in our last Newsletter that we were one of the three chosen charities to benefit from the **Waitrose Community Matters Collection** in the Cambridge Branch of Waitrose for November 2014. Each month, every Waitrose branch donates £1,000 (£500 in Convenience shops) between three local good causes. At the end of each shop a customer is issued with a green token to deposit in the box of the good cause they would most like to support.

Did you visit the store during November? I went along in **mid** November 2014 and took this photo which shows that November is a very good month to be nominated as a recipient for donations! We were delighted to receive a cheque for **£331.00** as our share in the November 2014 Cambridge Waitrose branch donation, which is an equal share of £1,000, and indicates that all three of the chosen charities for November had their boxes filled to the top.

Janice Pettitt suggested this means of fundraising and looked into what was involved. When our cause was accepted by Waitrose, Janice contacted the Committee at AMNET and we agreed on the suggested wording for the Community Matters box. Thank you Janice for this suggestion, for seeing through your idea and for collecting the cheque on behalf of AMNET.

We have, of course, written to Waitrose to thank them for this donation.



**Waitrose Community Matters Collection Box**  
(the AMNET section is the one on the right)

## Editorial



In the next edition of the Newsletter I would like to feature details of contacts for “hearing-help” organisations in different counties, as I am aware that not all our readers live within the Cambridgeshire boundary. If you live outside of Cambridgeshire please could you contact me (see back page for details) and let me know the contact details of where you attend for the sort of help that Cambridgeshire Hearing Help offers Cambridgeshire residents. There may be other members of AMNET living in your area who are unaware of whom to approach for help and advice. I will also contact Cambridgeshire Hearing Help myself to see if they can let me have contact details for organisations outside of Cambridgeshire.

I was fortunate to hear a talk by Cambridgeshire Hearing Help at the lip-reading class I attend at Addenbrooke’s Hospital. It was very interesting and informative. We were shown different telephones, alarms and door bells and personal listeners, so do please try to get along to one of their demonstrations, (see page 8), where you will be able to see demonstrations of equipment to help you hear better, whether or not you wear a hearing aid. We hope to have someone from Cambridgeshire Hearing Help come and talk to us at a forthcoming meeting. We are also hoping that Joy Badcock, the lip-reading teacher for Addenbrooke’s, will be able to come to one of our meetings. I have found the classes in lip-reading to be fascinating and thoroughly good fun, a means of boosting confidence in hearing ability in different settings and in understanding the complexities of the formation of spoken sounds.

In 2016 we will be celebrating 20 years since the first AMNET meeting. Alison Frank, our Chairman, would like to hear your suggestions for a notable speaker to come and address our special meeting which will be held in June 2016. It might take a whole year of notice to be able to secure certain speakers, so do please contact Alison as soon as possible with your suggestions. Her contact details can be found on the back page of this Newsletter.

Best wishes for 2015

Sally Hardy, Editor

## Forthcoming Meetings

**Summer Meeting - Saturday 11th July, 2015** - Doors open at 13.00 for our AGM, followed by a talk by **Debra Nash, CEO BANA.**

**Autumn Meeting - Saturday 28th November, 2015** - Doors open at 12.00 for our Christmas Bring and Share Lunch. We hope to follow this at 13.00 with a talk by an Audiologist from Addenbrooke's Hospital (tbc) and possibly a presentation by Cambridgeshire Hearing Help (tbc).

## 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 OTZ

### 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 OTB

### 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)

### Addenbrooke's 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's 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](mailto:sally.hardy3@btinternet.com) If you would like to make a contribution please telephone or email me.**