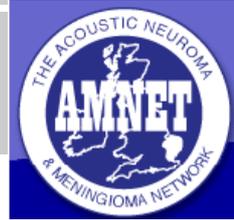


AMNET NEWS



Issue 57 Autumn 2013

Congratulations go out to
Arthur Davis
who celebrated his
100th Birthday on
September 10th 2013.

Doesn't this just brighten your day!!

Mr John Davis (Arthur's son), phoned me to tell me this amazing piece of news. Arthur Davis had surgery 25 years ago for the removal of an acoustic neuroma (probably not called a vestibular schwannoma then). At the time, he was the oldest patient to have had this surgery – at the young age of 75! I asked John what effect the surgery had on his father's life and he replied: "He gave up one of his allotments, but carried on with his bowling".



Arthur Davis celebrating his 100th Birthday

Apart from receiving a message from the Queen, Arthur had tea and cake at 3.00 on his 100th birthday at the nursing home and then his son John fetched him in his wheelchair to have champagne and pork pie at home with four generations of his family, including his two children, seven grandchildren, nine great-grandchildren and great-great-grandchild Alfie, aged four.

Arthur was born in 1913 in Camden Town, London and grew up in Kentish Town. As a teenager he worked as a toolmaker and then as an estimating engineer throughout the Second World War. When asked what the secret of living to be a centenarian was, Arthur said: "I have no idea why I've lived so long. I have always enjoyed good food and kept fit and I think that's very important. I've enjoyed all sorts of activities and sports throughout my life and carried on with them as long as I could - including bicycle racing, football, cricket and bowls". He has only recently had a few problems with his short-term memory and so moved to the Sanctuary Care nursing home.

Arthur is a long-standing member of AMNET, but has not been present at meetings. I am sure all readers will wish to join me in saying – **Congratulations Arthur** – we all hope you had a wonderful birthday and that you have many more happy years to come. Best wishes from all your colleagues at AMNET.

I wrote to find out how the special day went and am very grateful for the newspaper extract he sent from **Welwyn Hatfield Times 24** and grateful to Paul Christian, Editor, for his permission to reproduce details from the article and to be able to use the special photograph of Arthur Davis.

Next Meeting

Will be on **Saturday 23rd November, 2013** in the Boardroom at Addenbrooke's Hospital, Cambridge. Doors will open at 12.00 and you are welcome to bring a plate of food to share as this is our Christmas Meeting. This will be followed at 13.15 by a talk from **Mr Neil Donnelly**, Skull-base and Hearing Implant Consultant, Addenbrooke's Hospital.

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New Nurse Practitioner in Clinic 10

A new Nurse Practitioner has been appointed and has now started work in Clinic 10 (the ENT clinic) at Addenbrooke's Hospital, Cambridge. Nicola Folland has taken responsibility for NF2 patients in the clinic and will work alongside Juliette Durie-Gair. Nicky comes to Clinic 10 from Ward A5, which is one of the neurosciences in-patient wards, so you may have met her if you have been an in-patient there in recent years. Please contact either Juliette or Nicky if you have any concerns about your condition, whether due to symptoms or uncertainty about treatment options. If they are unable to answer your question directly, they will consult with the relevant specialist and get back to you.

Contact details: **Juliette Durie-Gair** and **Nicola Folland**
 Monday-Friday 09.00 – 16.00.
 Tel: 01223 348672 or via
 Switchboard: 01223 245151 or Bleep 154-600.

Juliette asked me to point out that occasionally both nurses may be out of the hospital, e.g. in clinics on other sites, in which case urgent queries can be directed to Anne Moralee, Secretary to Mr Axon and Mr Tysome on Tel: 01223 256051.

Indu Bahadur remains as Skull-based Nurse Practitioner (Mr MacFarlane and Mr Mannion).

to contact **Indu Bahadur**:
 Tel: 01223 245151;
 Minicom: 01223 274 604 or Bleep 154-175.

Space for your notes:

Summer Meeting

Held at Addenbrooke's Hospital in the Board Room on Saturday 22nd June 2013.

Informal Presentation by Helen Hewlett, Senior Physiotherapist, Neurosciences Department at Addenbrooke's Hospital

We were pleased to welcome **Helen Hewlett**, Senior Physiotherapist, to our Summer Meeting and she welcomed the chance to meet members and find out about our reactions to the input received from physiotherapists during vestibular schwannoma (acoustic neuroma) in-patient treatment at Addenbrooke's Hospital, Cambridge, and what physiotherapists can do to enhance our experience of recovery from surgery.

Helen works in the NCCU (Neuro Critical Care Unit), Neurology and the Neurosurgery Wards at Addenbrooke's Hospital in Cambridge and pointed out that vestibular schwannoma and meningioma patients make up only a small part of that workload. She has a team of 10 physiotherapists working with her - not all are full-time. There are two reasons for patients needing input from physiotherapists as part of their treatment for vestibular schwannoma – either balance problems or facial palsy as a result of the condition or from damage caused by treatment.



Helen Hewlett (left) with AMNET members

In the translabyrinthine approach used for the surgical removal of acoustic neuroma, the vestibular nerve is cut to remove the tumour. This nerve branches to provide hearing and balance and so the patient will be deaf on one side and balance will be affected after surgery. Some people will be aware of change to their balance as the tumour grows, and this might have been part of the reason why an individual made contact with their GP. Vestibular schwannomas are slow-growing benign tumours and in many individuals, the brain will have adapted to perceived changes in balance as they occur.

Physiotherapists have noted that the size of the tumour seems to show no relevance to the balance problems experienced post-surgery – some people are able to stand and balance immediately whilst others are less able.

Within Addenbrooke's Hospital, Cambridge, a physiotherapist will currently visit a patient on the day following surgery for removal of a vestibular schwannoma. As part of the neurosciences team, the physiotherapist on duty - will be aware of the individual patient's condition following their surgery, their potential problems with balance or facial palsy will be identified and the level of physiotherapy input and specialist help needed, (e.g. speech and language therapist), can be planned. It is routine that this first visit will involve the physiotherapist leaving a **sheet of focus-based balance exercises** to be worked through by the patient. This is because the theory of balance is to move as soon as possible so that the brain can re-learn to balance. With only one vestibular side working now, learning is achieved by pushing the brain to its limit by doing the exercises on the sheet. Helen explained that in those patients who do experience balance problems, their symptoms will not improve until the exercises have been worked through. She added that the balance and dizziness rehabilitation exercises included in the focus-based exercise sheet could work for patients in the **“watch, wait and re-scan”** group, where their tumour is pressing on and causing damage to their vestibular nerve. There is no evidence that this would work, but it may be worth trying. Helen stated that **retrospective healing of balance** was also possible by working through focus-based balance exercises. She added that any exercise is good, especially if it is something you enjoy.

The facial nerve will have been monitored by surgeons during surgery and any potential facial nerve damage will be noted in the patient notes. Due to the expertise of the neurosurgical team at Addenbrooke's Hospital, the majority of cases of facial palsy experienced by patients in the post-surgical period currently tend to be a temporary response to the surgery and will recover. The physiotherapy department have **facial nerve exercise sheets available (on request)** which encourage the use of gentle massage and exercises to aid recovery of stiffness and eye care exercises to help with blinking [*please see my personal comment later in this article*]. Helen offered some general advice about facial weakness/facial stiffness. For women – gentle massage is very beneficial to the underlying muscles and can be done daily when applying moisturizer. For men – gentle massage to the facial muscles can be done as part of the daily shaving routine.

Patients needing further input with balance issues at the time of discharge from hospital will be referred to a local physiotherapist with a recommended exercise regime. Addenbrooke's Hospital also has an out-patient neuro-physiotherapy (balance clinic), which is run by Carole Moss.

Helen asked us to break into small groups to talk about our experiences of physiotherapy as in-patients at Addenbrooke's Hospital, Cambridge and to consider:

- ◆ Our expectations of physiotherapy
- ◆ Our experiences of physiotherapy
- ◆ Whether physiotherapy helped us to achieve what was needed during our stay
- ◆ Any specific questions we might have.

At this meeting of AMNET, members present were representative of our Charity as a whole - with some members having had surgery 20 years ago and some more recently; some who were in the “watch, wait and re-scan” group and others who had opted for radiotherapy treatment. It became clear that only patients undergoing surgical removal of a vestibular schwannoma, currently seem to have any contact with a physiotherapist.

Group Feedback

We responded that we were grateful for the excellent service provided by physiotherapists and grouped our comments as follows:

timing of visit to patients after surgery for removal of a vestibular schwannoma, might

need to be reviewed since most of us found that we felt too un-well, due to vomiting, on the day after surgery.

pre-op assessment - a physio pre-op visit, or visit on admission to hospital, **to assess the patient before surgery** and to explain what the patient may experience in the post-surgical period would be useful (Helen answered that this is currently not an option due to physiotherapy resources and funding issues). Certainly, to be given the focus-based exercise sheet at this stage - would give the individual the chance to prepare to feel different post-surgically as **some advice would be useful**.

paperwork issue - there was a lot of **paperwork** around their bed area and the exercise sheet became swamped by this

visual problems – font-size on the document is small and can be difficult to read, especially when eye ointment has been applied. However, this can be helped by involvement of visitors/relatives.

weekend discharge from hospital - vestibular schwannoma surgery is routinely carried out on either Mondays or Thursdays at Addenbrooke's Hospital and one member commented that having their surgery on a Thursday resulted in a **weekend discharge** from hospital, without review by a physiotherapist – so the need for further input with balance issues may be missed when this happens.

follow-up by phone? - we questioned whether follow-up by phone by physiotherapist could be a possibility when a weekend discharge from hospital occurs.

One member, who had surgery more than 10 years ago, commented that she was helped with walking by a physiotherapist after surgery, but did not have any help with her face or dry eye, and this had been disappointing.

The general view amongst members present was that although facial palsy might only be a temporary side-effect of surgery today, it can still be frightening to look and feel different, and it would be very helpful to have some advice on facial exercises, massage technique and how to manage a dry eye. Helen acknowledged this by saying that there seemed to be a general theme emerging from our comments about this.

Other comments from members included more common long-term balance problems:

- ◆ difficulties experienced in crossing the road
- ◆ height of steps or kerbs
- ◆ access to buses, especially if seated upstairs
- ◆ spatial awareness

One member commented that the **use of night lights was useful** - when trying to locate the bathroom at night. Another member had found the balance clinic to be very helpful.

*[On a personal level, I found that my facial palsy slightly worsened about 10 days after surgery and the facial muscles on the good side seemed to be pulling the palsied side. As **Indu Bahadur** was still a point of contact in that immediate post-surgery period, I phoned her and she sent me a copy of the sheet entitled “**Exercises for facial weakness**”, which is the Patient Information document published by the Department of Neurosurgery and referred to earlier in this report. This included pictures of Helen Hewlett demonstrating:- general exercises, some for the lips, stretches, jaw exercises, exercises to help close the eye, facial massage and details about eye care, taping the eye shut, techniques for inserting drops into the eye, gels and ointment. I would have found this extremely helpful from day one and wonder why this does not happen on a routine basis].*

As **retrospective healing** may be possible by doing the exercises on the focus-based sheet and as they might also be helpful to members in the **watch, wait and re-scan** group, or by those who have had **radiotherapy** or **radiosurgery**, Helen has sent copies of the exercise sheets to Alison Frank, for distribution as required. If you feel you could benefit from physiotherapy exercises, please contact Alison Frank on: 01953 860692. If, however, you feel you need to be seen by a physiotherapist due to your balance problems, please contact the physiotherapy department at Addenbrooke’s Hospital (Tel: 01223 256317/01223 245151 Ext. 56317), if you live in the Cambridgeshire area, or contact Indu Bahadur/Mr MacFarlane (see p.2 for contact details), if you live outside Cambridgeshire, (for physio referral, as not all physiotherapists will be aware of vestibular rehabilitation), or your GP for a physiotherapist referral.

Alison thanked Helen Hewlett for coming to talk to us and for her honest and open approach in listening to our concerns.

Sally Hardy

Do you travel by train regularly?

One of our members, **Fiona Pike**, has the following information about rail travel, which could save you a little money.

“A friend recently mentioned that she has a **Disabled Person’s Railcard** and is eligible to buy this card because she has hearing aids and all the proof required is the card/book she uses to get new batteries for them. This is fine for those who have a hearing aid, but what about those who choose not to wear one?

I was uncertain what form of identification I could get that would allow me to be considered for a **Disabled Person’s Railcard**. My initial thought was that I would have to approach my GP and ask for referral to an ENT clinic for a hearing test. Since I had my operation for acoustic neuroma in 2001, I am right-sided deaf and have not had a hearing test since 1999.

Chris Richards (our former Editor) had studied hearing problems, so I sent her an e-mail. She suggested that I e-mail Hertfordshire County Social Services (my local council). I completed their on-line form applying to be registered as disabled and within a few days I was sent a **Disabled Person’s** card. On looking at the card, I realized that the detail on it was vague and not official looking – no entry of my full name and address on it, so felt it might not be accepted by **British Rail**. I approached my GP about having a hearing test, which would give me an official letter confirming my single-sided deafness, but he said that due to financial restraints he could not authorise a hearing test. However, he would ask his receptionist to look at my notes and if there were any letters from Addenbrooke’s Hospital confirming my deafness, then I could have a copy. The receptionist did this and I attached the copy to my application form for a **Disabled Person’s Railcard**, plus my £20 cheque and received the card almost by return. (Nowadays patients are issued with a copy of any relevant correspondence to their GP).

The card costs **£20/year** or **£54** for a **three-year card**, which is considerably cheaper than a **Senior Railcard**, and allows a companion travelling with me to pay the same fare as me (one third off most rail fares throughout Great Britain).

I hope this information may be useful for other members who travel by train.”

Fiona Pike

[Having looked at the information Fiona sent me, to be eligible for a **Disabled Person's Railcard** you might qualify if you: have a **visual impairment**, a **hearing impairment**, have **epilepsy** or are in receipt of a **disability-related benefit**.]

For those without a computer, please telephone:

National Rail: 08457 48 49 50

– open 24 hours a day, and ask for a form to be sent to you.

For the on-line form



go to:

www.disabledpersons-railcard.co.uk

Helpful Hints

Eye drops – Some of us have found that due to irritation/soreness/allergy we choose eye drops or artificial tears that are preservative-free. These are usually dispensed in “single-use” containers or minims. Although they say “single-use”, if you retain the plastic twist-off part, then you should be able to insert it back into the top of the container. If you do this, do not touch the end of the plastic tip, so that you avoid any cross-contamination. This should give you 4-5 applications from one “single-use” container, and thus save your prescription charge. Carmize 0.5% vials actually say “re-closable vials” on the inner packet and when we compared these to Celluvisc 0.5% and Celluvisc 1% “single-use” vials at a meeting, we found it possible to re-insert the plastic tips back into the vials.

(Heidi Pratchett and Sally Hardy)

Spatial awareness/balance in the dark – If you have difficulties finding the bathroom at night, due to changes in your spatial awareness perception or balance in the dark, plug in a night-light to a relevant plug. This provides enough light to see where to go. *(AMNET member at a recent Meeting)*

Update by Peter Lawrence

Many members of AMNET will remember accounts we have reported about the progress of Peter Lawrence, a Cambridge zoologist, who has worked for the last 40 years on genetics. For those readers who are new to AMNET News, the history of Peter's diagnosis of acoustic neuroma (vestibular schwannoma); his decision-making, “watch, wait and re-scan”, Gamma Knife treatment and then neurosurgery in 2011 can be found in back issues of AMNET News – please see: Issue 39-Spring 2007, Issue 44-Autumn 2008 and Issue 51-Autumn 2011 or go on-line to our Website:

www.amnet-charity.org.uk and look in “Library”.

“This is the latest news regarding my vestibular schwannoma. Keen followers will remember that my poor tumour has been insulted on two major fronts. First it got blasted by gamma rays in 2008 and then it had the relatively rare insolence to start to grow again, so that in 2011 it had to be removed by Mr David Moffat and Mr Robert Macfarlane at Addenbrooke's. However, they left a small portion of the tumour “capsule” as it adhered so strongly to the brain (perhaps because it had been cooked by the irradiation). This worried me but they told me that the bit of capsule probably would not survive. I even checked this prediction with another neurosurgeon in Italy, who is a friend, and he told me that yes it was common to leave some capsule behind and normally that was not a problem. It is not too clear what a surgeon means by the capsule, and I wonder if it is the same thing as described by histologists; the latter reporting only a sheath of a couple of microns thick, which would be too thin to see.

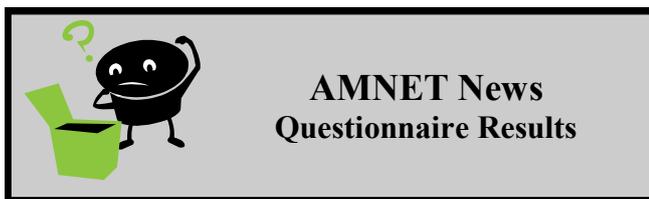
But, the important thing for me was that one year later, in 2012, there was no sign of the tumour, but, clearly not completely confident, Mr Moffat advised a further MRI in 2013. I have just had that MRI and once again there is no sign of a “residual or recurrent tumour”, so I can begin to forget about the damn thing. I am to have another MRI in two years, to make sure.

It was interesting to me that the indentation in the cerebellum, caused by the tumour, (which was some 2cm in diameter at removal), has now gone and the brain had returned to its normal shape. However, the double vision I have had for many years, and was perhaps due to the tumour impacting

on the 6th cranial nerve, (no-one seems to know), has not improved. That was a bit disappointing, as I had hoped that at least my dependence on prisms in my glasses might be ameliorated.

However, many reading this magazine, will know that single-sided deafness is no joke – the inability to hear a voice in a noisy background, the inability to locate sound – well they are both serious handicaps. But I, and many others, will be grateful to the skills of our neurosurgeons, who have saved our lives and preserved their quality. Peter”

[Thank you for sharing this with us all Peter – it will be very encouraging to anyone else who finds themselves in a similar position to you - to hear how well you are doing. Ed]



On behalf of the AMNET Committee, we would like to say thank you to all readers who took the time to respond to the Questionnaire which was sent out with your membership renewal. 137 questionnaires were sent out and 45 returned, so the response was high (33%). We hope the results are representative of our members as a whole.

As Editor, I would like to say a big thank you to Rachel Pearson, our membership secretary for making sure that each of our members was given the chance to air their views on the newsletter. Carol and Mick Clothier have done a very professional job in analysing the returned data, which is available in full (in paper form) on request from Alison Frank (Tel: 01953 860692) and will be available at forthcoming meetings, or can be viewed on the AMNET Website: see www.amnet-charity.org.uk.

As you will know, AMNET is a self-help and support group, based in the East of England, for anyone with a diagnosis of acoustic neuroma or other skull base tumour. Committee members of AMNET are all members of the organization, like yourself, with a desire to keep lines of communication open between members and we do this on a purely voluntary basis.

From your answers it would seem that the most interesting articles in Issue 56 of AMNET

News were: a) single-sided deafness clinic database (58%) and b) information about action on hearing loss feature (58%). Our “helpful hints” column rated next highest (53%) so PLEASE do keep these coming in. The article on “reader response re wireless hearing aids” was appreciated by 49% of readers – so it would be very interesting to hear from other readers on this topic. You appreciated the “heart-warming feature from one of our members” (49%) so I hope you will also enjoy our feature on the front page of this edition about our member Arthur Davis.

Please be reassured that **any** details written about talks given by professionals at our meetings are checked by the professional giving the talk before submitting the newsletter for printing. It can be difficult to relay this information in a form that is understandable to all, especially if you were not able to be present to hear what was said. For most members it would seem that we manage to get the information to you in an acceptable format, for some it is too technical and for others it is not technical enough. We would welcome anyone who could contribute their time to help in research into matters that affect members of AMNET, even if this is on an occasional basis or for specific areas.

It was very reassuring to see that 14 members felt they were interested in contributing an article or information about their experience, as this is very much the aim of the newsletter, and in this issue we have been very fortunate to have input from a number of different members – THANKYOU.

Some of the issues relating to subjects like use of colour, availability of the newsletter via e-mail, are items that need discussion at a Committee Meeting, as this will affect expenses. This information will be fed back to you in a later edition of the Newsletter.

It has been really useful to me as the new Editor, to hear your comments and to gauge the sort of articles that will be of most interest to you. I will try to make that possible, but in the meantime, if there are any other general points you would like to make that might not have been included in the questionnaire, please do not hesitate to contact me or any other member of the Committee.

Many thanks to you all - Sally Hardy, Editor.

From “watch, wait and re-scan to Gamma Knife Radiosurgery and then Neurosurgery for removal of an acoustic neuroma and STILL smiling.

This is an account by our member **Jeanette Fickert**, who was diagnosed with a vestibular schwannoma (acoustic neuroma) in 2008. At that time Jeanette lived in Milton Keynes and was under the care of Mr Moffat. She now lives in Birmingham, but remains an active member of AMNET. If you are also a member of BANA, you may have seen this account by Jeanette in their Summer 2013 issue, but for those of you who are not, then here is Jeanette’s inspirational story so far.

“In September 2008, just months after I lost my dear Papa, I was practising yoga like I do every day and attended my weekly yoga class only to find that, yet again, I wasn’t very steady on my feet during my balancing postures. Then came the strange waking up one morning to a spinning room and falling back onto my bed when I tried to stand up! The feeling of nausea didn’t become apparent until a couple of days later. I visited my GP as I was concerned I wouldn’t be well enough to fly, as I was due to go to my annual yoga holiday in France. I was prescribed a nasal spray, then anti-sickness tablets so that I could fly, and from memory, some ear drops too.



This is me, before any treatment, with my adorable nephew, aged 6 months.

Whilst away, I spoke with my friend’s husband, who is/was also a GP. He suggested a hearing test and an MRI scan upon my return to the UK. Within a week, I was back to see my GP, who gave me a hearing test and made the discovery that my right ear had lost some of its performance. An MRI revealed an AN. It was suggested I have annual MRI scans and “watch, wait and see”.

So I had yearly MRI scans. In 2010 I moved to Birmingham, as the drive from Milton Keynes to Birmingham on a weekly basis for work, was too much and my chosen consultant, Mr Richard Irving is based there.

Shortly after I moved, the results from my annual MRI revealed further growth, so it was suggested that I have surgery within a couple of months. I was shocked, and asked whether or not there were any other options available to me. Due to the size of my AN, just under 2 cm, I was offered the Gamma Knife procedure. My research sent me to see Mr Jeremy Rowe in Sheffield and my procedure went ahead on 15.09.2010. It all went smoothly, albeit somewhat painfully, when the frame was fitted. I was only away from home for one night and needed to take just a couple of days off work.

Sadly, the happiness didn’t last, as I experienced facial palsy at the end of January 2011, which scared me terribly. Not having been warned of this, I thought I was having mini-strokes. It was also difficult to contact Mr Rowe, and in fact I never did. Someone from his office called me several days later. These strange facial spasms lasted about 9 months, each lasting from a couple of minutes to no more than 5 minutes - not at all painful - just scary and noticeable. It stopped me from driving and I remember, very early on, when they had just started, I was on a bus home, when the driver saw my face and pulled over and asked if I needed him to call 999 for an ambulance! There were a few more instances like that I remember – one being a nurse at the checkout who also thought I was having a stroke. Thank goodness they passed. Moving forward, my next annual MRI scan (2011) showed a slight swelling, but the core of the tumour was black, which was a good sign and an indication that the radiosurgery was killing the centre of the AN and the blood supply was being cut off. I was also sending these scans by CD to a Derald Brackman in LA, who was incredibly helpful and his input was so valuable. It was comfort-

ing for me to hear the opinions of other surgeons and consultants, other than just mine here in Birmingham.

In August 2012 I had my regular MRI. To say I was speechless when I got the results - is an understatement. My brother came to all my follow-up scan appointments and talked me through all the positive comments and further steps I would need to take or wait for. Mr Irving advised us that day that the radiosurgery had not worked and my AN had, in fact, doubled in size since the Gamma Knife procedure two years before. I needed surgery as soon as possible and certainly within the next two-three months. Then we bombarded Mr Irving with questions and questions and a few more questions. I thought if I could put my feet up over the Christmas period, I could start the New Year refreshed and AN free!

On 08.12.2012 I arrived at the BMI Priory Hospital in Birmingham for my op, the translabyrinthine procedure, due to take place that same day at noon. It was delayed by a couple of hours, but I came round some 6 hours later, to be met by both my two brothers, (one of whom had flown in from Toronto a couple of days before the op, to help and support me), and all three consultants – Mr Richard Irving, Mr Robert Walsh, the neurosurgeon and Mr Huggins, the anaesthetist. They all asked the same question: “can you smile for me please?” The op was successful, with no facial paralysis, which is fantastic news. They had to leave a slither of the tumour in situ, as I’m told it was too tightly wrapped around the trigeminal nerve and they wanted to preserve this delicate nerve and avoid facial paralysis. We will have to wait and see what happens with that tiny slither.



This is me with the bandages removed

My bandages came off on the following Friday and I left hospital the next day, after my 7 day admission. I stayed with my brother and his family, as it was suggested I shouldn’t stay on my own for the next few days. On 21st December I had my stitches out and shortly after that I went to my mum’s for a long weekend and then home. It seemed like I’d been gone for months, rather than just three weeks.

Fortunately my girlfriend and her husband came to stay on 30th December 2012 for a night and not only experienced, but assisted me with my CFS leak - something I had been warned about. A quick trip back to the hospital that morning, the 31st December 2012, to have Mr Irving stitch me up again, where the wound hadn’t quite healed as well as he had hoped. Whilst he wrapped my new bandages around my head, my body had had enough and I passed out momentarily. How embarrassing was that! My girlfriend was somewhat worried as her petite frame was trying to hold me upright on my bed so that Mr Irving could continue with the bandages. I’m told he didn’t even batter an eyelid – “it happens”, he said afterwards. All I could do was apologise. So, there I was, back with my brother and his adorable family, for a few more days. The headaches were uncomfortable, but under control with the prescribed painkillers.



This is me back home and smiling

Once again, I went back home and was back at work within days. In fact, I’d spent a couple of days in the office before the CFS leak. I’d managed to celebrate my 52nd birthday on 24th December too, went out on Christmas Day for lunch as well as a long Boxing Day lunch. I’d lost one and half stone in weight, so could afford three consecutive days of enjoying tasty lunches with family and close friends.

Jeanette Fickert article continued from previous page

Early in the New Year (15th January 2013) my second lot of stitches came out and I have felt on top of the world some days and very down others. My energy levels have been crazy, sleeping 8-10 hours solid or just 3 hours, for no particular reason. I've had up to three-hour naps some afternoons too. There have been a few days where I've felt I'm stepping one step forward and three back. There are days where I feel unwell, so I work from home. It's all behind me now and I just need to remember I've undergone major brain surgery. I need to be mindful and grateful to the wonderful consultants, my family and friends who have supported me throughout this whole journey.

Best wishes to anyone who has recently been diagnosed, is about to have radiosurgery or an operation. There is always light at the end of the tunnel and remember, you are not alone. I'm terribly excited about the future and take every day as it comes. And I wake up smiling every day “

Jeanette Fickert

[Jeanette asked me to point out that she found the support she received from both BANA and from AMNET to be invaluable. She spoke to a member from BANA and found that information she was able to access from both organizations helped her enormously. As a consequence she attended the Communications Course run by Chris Richards and Alison Frank at Addenbrooke's Hospital in September 2013, as she would like to offer her support and encouragement to other people who have received a similar diagnosis or are at different stages in their treatment journey. Thank you Jeanette for sharing your story with us and for your continued involvement with AMNET. Sally Hardy]

Audiology Department, Addenbrooke's Hospital - introduce a new hearing aid maintenance training session

Hearing aids need regular servicing and maintenance to ensure they continue working optimally. Although some patients already do this



maintainance themselves, many patients come to the hospital open repair sessions or the local hearing aid help sessions, run by local charities: ADAPT, CAMTAD, Hertfordshire Mobile Advisory Service and Uttlesford Hearing Help.

This basic maintenance class teaches patients to care for their hearing aid, including fault finding, cleaning and retubing. Patients are often concerned they will break their hearing aid. The class gives them the confidence to take the aid apart, to clean it properly, and thus to feel more independent.

If a patient or a relative/representative is interested in attending the class, they should contact the Audiology Department for more details.

Tel: 01223 217 797

AMNET AGM held on Saturday 22nd June 2013 in the Boardroom at Addenbrooke's Hospital.

Apologies: Apologies and proxy forms were received from 14 members.

Minutes of last meeting: were published in Issue 54, Autumn 2012, of AMNET News and are available on the AMNET website: <http://www.amnet-charity.org.uk/> in the "Library and Back Issues" section. There were no objections, so these were signed by Alison Frank.

Chairman's Report: (See page 12)

Treasurer's report and accounts for last year: Carol thanked Jo for her help with the financial history and with taking over and also thanked Rachel, on a personal note. We were very grateful for donations of £1,500 from Heidi and £100 from Paul Clifton. Our balance, to be carried forward is £5,393.11 this year. Basically if we were dependent on subscriptions, we would not cover our costs. She therefore asked whether we need to consider fundraising more generally at our meetings or whether we should increase the subscription rate. This is open to discussion. The accounts had been audited free of charge, by Gilberts, Accountants, Pendragon House 65 London Road, St. Albans, Herts. AL1 3BN. It was proposed by Joanne and seconded by Rachel and unanimously agreed that these accounts be accepted.

Provision of bursaries: We are proposing to provide a bursary of just over £500 for Kate Burton, Consultant Radiographer, to attend a 3-day conference. The subject is relevant to us all as it will be about her work on vestibular schwannomas. The subject of bursary provision will be reviewed on a person by person basis and dependent on where a conference is to be. Those present at the meeting were happy for this to proceed. This motion was proposed by Carol and seconded by Margaret Alcock.

Election of officers to the Executive Committee: John will stand as Secretary this year, but will not be able to do so after this. He would be happy and willing to hand over and help anyone wishing to take on this role. This announcement was proposed by Bronwyn and seconded by Jo. Please note that Mick Clothier has also been co-opted onto the Committee as a general member, but his name did not appear on the Agenda for the AGM. (see box below for other members of the committee).

There were no written questions or opinions submitted by members.

Any other business: it was agreed that we should donate gifts for the Christmas Raffle rather than buy them. As a way of raising funds, it was also discussed whether members would like to have a raffle at each meeting. This is open to discussion. The AMNET website needs revamping – we urgently need a skilled person to take on this role.

The meeting finished at 3.10pm.

Election of Officers and Committee:

Following a proposal by Sally Hardy, seconded by Rachel Pearson, the following were elected en bloc:

Chairman:	Alison Frank
Treasurer:	Carol Clothier
Secretary:	John Peartree
Newsletter editor:	Sally Hardy
General Members:	Janice Pettitt, Bronwyn Lummis, Charlie Lummis, Mick Clothier

AMNET AGM held on Saturday 22nd June 2013 in the Boardroom at Addenbrooke's Hospital.

Chairman's Report

Welcome to the beginning of AMNET's 17th year. This has been a year of change for the committee on both the charity's and personal levels. After many hard working years, Chris has handed over the Editorship of the newsletter to Sally Hardy. Sally has worked extremely hard at producing the last 2 editions of our highly valued newsletter. It is a vital link for those AMNET members who cannot attend meetings and its survival was very important. A questionnaire is being sent out soon so you can express your views about the newsletter - please fill it in and return it so we can gauge your feelings. Carol Clothier has taken on the Treasurer's role very efficiently from Jo, who retired last year. We are grateful to all these members for their sterling efforts on behalf of AMNET. There is a lot of behind the scenes work being carried out by other members of the committee: John, Janice, Bronwyn and Charlie. Rachel is not on the committee, but fulfils the membership secretary post ably, in conjunction with Carol. Rod Slade has resigned from the committee and from distributing the newsletters. We have had some offers to fill this post, for which we are grateful. As a thank you to Chris and Jo, AMNET would like to award them life membership – I hope you agree that this is just reward for all their hard work.

We have again learnt from talks from our speakers. Consultant neurosurgeon Richard Mannion came last July, skull-base nurse practitioner Sally Taylor in November and Karen Johnson from Facial Palsy UK in April. AMNET appreciates their giving up their time to come and talk to us. Heidi has again been instrumental in raising funds, this time from Harwich and Dovercourt High School. The students kindly nominated AMNET to receive funds from their Prom, which John collected on our behalf. We are inviting Addenbrooke's staff (from Clinic 10) to apply for bursaries from AMNET, with the proviso that they come and speak to us and/or write an article for the newsletter.

I would like to finish by thanking everyone who has helped AMNET during the last year. Best wishes - Alison Frank.

EDITORIAL

It has been really encouraging to receive a number of contributions from AMNET members for inclusion in this edition of the Newsletter. Please keep them coming!!! Any more "Helpful Hints" that you care to share would be very welcome. It would be very interesting to hear from other members about their experiences with wireless hearing aids and how they have boosted their ability to hear clearly at meetings or lectures by linking their hearing aids to other aids. In our next edition, I would like to feature my recent experience of using a loop system in my Phonak wireless hearing aid, how this can be linked to a TV loop system or to a person making a speech. We are able to try before we buy, and I will talk of my experience in doing this through Audiology at Addenbrooke's and have detailed how this can also be done through CAMTAD, (see page 14) ,in case this can be helpful to you in the meantime.

Our next meeting will be our "Christmas Meeting", on November 23rd, 2013. Doors will be open in the Boardroom at Addenbrooke's Hospital from 12.00 and we would be grateful if you could bring a plate of food to share with others. Also, please could you consider bringing something as a raffle prize. There should hopefully be some tasty Christmas treats for sale that have been produced by various members. See you there.

Sally Hardy, Editor

ACTION ON HEARING LOSS News

A potentially groundbreaking research project in Oxford on understanding how changes in the brain cause tinnitus could lead to future therapies ...

A three-year PhD study by Joshua Gold and supervised by Dr Victoria Bajo Lorenzana at the University of Oxford will run from October 2012 until September 2015. The following information is taken from the Action on Hearing Loss Website: www.actiononhearingloss.org.uk/your-hearing/biomedical-research section and was downloaded on 8th October, 2013, and I am including this here as I realize that not all members have access to a computer.

“Tinnitus often occurs after a hearing loss and evidence suggests that this might be due to nerve cells in the brain becoming extra sensitive (or hyperactive) as they adjust to the loss of sound signals from the ear – just like the hum that you’d hear if you turned up the volume on a stereo. This hyperactivity seems to be linked to how the brain ‘maps’ different sound frequencies, particularly for sounds affected by ear damage.

The **aim** of this project will investigate brain ‘mapping’ reorganisation and changes in nerve cell activity that occur after hearing damage, which is thought to have caused tinnitus.

After identifying areas of the brain with abnormal activity, the researchers will attempt to reduce the sensation of tinnitus using a new scientific technique – called **optogenetics** – in which genetic and optical methods are used in combination to manipulate the activity of nerve cells.

The team will focus on the nerve cells in the reorganised parts of the brain. The technique involves putting light sensitive proteins into the nerve cells that can then be turned ‘on’ and ‘off’ with light. By turning the proteins ‘on’, the nerve cells should turn ‘off’, which should reduce the tinnitus.

The **impact** of this project should provide crucial insights into how tinnitus is generated in the brain, and should reveal whether optogenetic manipulation of the ‘reorganised’ nerve cell circuits help to reduce the sensation of tinnitus.

If the researchers are successful in reducing or even eliminating the sensation of tinnitus by using

their combined light and genetic approach, this will indicate a promising avenue of further research.

Further studies would work towards finding safe and effective ways of correcting these neural circuits in humans and could lead to new treatments, not only for tinnitus, but also for other conditions involving abnormal activity in the brain.”

[Grateful thanks to Action on Hearing Loss for permission to reproduce this article here].

ACTION ON HEARING LOSS support BBC Chief in calls for TV actors to speak more clearly

[This feature caught my eye and thought you might be interested as the darker evenings approach and we find ourselves indoors more]

In a recent interview in the Radio Times, Tony Hall, new director for the BBC, complained that actors aren’t speaking clearly enough in TV drama. 87% of respondents to the Action on Hearing Loss membership survey said background noise affects their ability to hear speech on television and more than half have switched off because of it.

As a response to this claim from Tony Hall, Roger Wicks, Director of Policy and Campaigns for Action on Hearing Loss said “television producers can make programmes more accessible for people with hearing loss by following the BBC’s best practice guidelines. Presenters and actors should be coached to keep dialogue clear and the level of background music should be reduced and audibility problems eliminated before material is recorded. One in six of the population has some form of hearing loss and they should not be ignored.”

[Posted on Action on Hearing Loss website 17/7/13]

To find out more visit the **Access to television** campaign page for further information and to find out how you can **make a complaint** if you experience problems with the clarity of speech in a television programme at:

www.actiononhearingloss.org.uk

Gorki Duhra, PR Officer at Action on Hearing Loss: Tel: 020 7296 8057 or e-mail: Gorki.duhra@hearingloss.org.uk

More about Tinnitus

To balance the earlier research article about Tinnitus I thought I would refer you to a BLOG that **Action on Hearing Loss** run on their website. On Tuesday 8th October 2013, James Robins posted the following: “Tinnitus is often misunderstood and some of the myths surrounding it can be misleading for those with the condition, causing anxiety and even preventing people from accessing the help they need.”

On the BLOG James then quotes Action on Hearing Loss Senior Audiology Specialist **Gemma Twitchen**. Gemma attended the British Tinnitus Association Annual Conference in the British Library, London and found that one particular presentation entitled ‘dispelling the myths about tinnitus’ really caught her attention. She says:

“even though we may not have a cure yet, there is a lot of support available which enables people to manage the condition. Therapies such as cognitive behavioural therapy, tinnitus retraining therapy and sound therapy, as well as hearing aids, tinnitus relaxers and other devices, can all be of benefit to many people with the condition. So with the right advice and support, it’s possible to find a management strategy which can help reduce the impact the condition has on your life”.

For more information on this go to: www.actiononhearingloss.org.uk and follow the link to: ‘**tinnitus, myths and truths**’ and ‘**how you can manage tinnitus**’.

For a more ‘visual’ help on this subject, **Mr David Baguley**, Principal Audiological Scientist at Addenbrooke’s and also a member of the Professional Advisers’ Committee for the **British Tinnitus Association**, features in a 5-minute video, where he explains the possible causes and effect tinnitus often has, such as stress and anxiety, plus how to deal with them. If you do not have a computer, ask someone at your local library to help you access this video on the internet.

To see the video go to: www.tinnitus.org.uk/tinnitus---the-video.

News from CAMTAD

At the 2013 CAMTAD AGM the decision was taken to form a Charitable Incorporated Organisation and to change the name of the Charity to **Cambridgeshire Hearing Help**. They will not abandon the name CAMTAD and will run the two names in tandem for a while.

The following information may be helpful if you do not have internet access. CAMTAD have given permission for me to reproduce the information from their website

(www.camtadcams.org.uk/hearing-help-equipment):

“The most useful form of hearing help equipment is a hearing aid. Most people with a hearing loss will get better hearing by using an aid, but it may not be sufficient amplification in every situation.

Hearing Help equipment is designed for particularly challenging listening environments – hearing voices on the telephone or TV or hearing the conversation at a meeting or family event. Doorbell and telephone ringer alerts are also essential to keeping safe.

At CAMTAD

- We have equipment to lend for a month from our Cambridge office so that people can try before they buy and get an idea of the benefits that new equipment may bring.
- We offer advice at our drop-in-hearing help sessions, over the telephone or to visitors, by appointment at the Cambridge office.
- We have a regular programme of displays and demonstrations around the county.

We can also refer people to the local authority sensory services team for an assessment of need and provisions of assistive equipment. Telephone our Contact Centre.”

If you think a referral to the sensory services team would be helpful to you, please phone:

0345 045 5221

The next display and demonstration of hearing help equipment will be on **Friday 29th November, 2013**, from 10-12.30 on a drop-in basis at: Huntingdon Community Church, 83a High Street, PE29 3DP.

In the August Newsletter, Frances Dewhurst discussed the changing financial implications that the NHS is having on CAMTAD. She reassured readers that she is “working closely with “Healthwatch” [formerly called “Links” - a patient-representative group] and other charity colleagues to make sure our voice is heard, and the signs are that doctors and other professionals involved are willing to listen to what we contribute”.

News from BANA

At the BANA National meeting and AGM in June 2013, **Mr David Moffat**, former Consultant in Otoneurological and Skull Base Surgery at Addenbrooke's, gave a presentation entitled ‘AN management over a 30-year period in Cambridge’ and **Mr Gary McFeely**, Lead Radiologist from St Bartholomew's Hospital Cyberknife Department, gave a presentation on the development of this treatment and its use in the treatment of ANs'. Both of these talks were recorded and are available on DVD from BANA's office. If you are interested in obtaining either of these DVD's please contact Julie Moore, Co-ordinator (Thursday or Friday) at the BANA Office, and see our back page for contact details. For those members who missed our Autumn Meeting in 2011, Mr Moffat gave a similar talk and this could be a chance to hear his presentation. One of our members, **Helen Bush**, gave an account of her **Cyberknife Experience in July 2011** at St Bartholomew's Hospital, London (see our Issue 53 Summer 2012 Edition of the Newsletter). It will be interesting to see what view Mr Donnelly and the skull-based team have on this form of treatment for acoustic neuroma patients, when he comes to speak to us at our next meeting.

There was a very interesting feature in **Headline News, Autumn 2013 on Dry Eye Syndrome (DES)**, which their member, Steve P, had seen on the **Blood Donor** website:

<http://www.blood.co.uk/the-donor/summer-2013/dry-eye-syndrome/>

This is a small extract from that report for your interest:

“NHS Blood and Transplant has been working with ophthalmologists for many years to provide a special treatment for these patients. We can prepare artificial tears from their own blood which is effective because blood contains many of the same substances found in normal tears.

Unfortunately not all patients with DES are suitable for artificial tears. Patients must be healthy enough to give blood. If they are suitable, they will go along to a blood donor centre where their blood is collected into a special type of blood pack. This is then diluted with saline and transferred into sterile glass dropper bottles, ready to be frozen. These little bottles are issued to the patient to store in their own freezer at home. Each day they thaw out one bottle and apply the eye drops as required.”

It would be interesting to hear if any of our members are using this facility and if so, how they are getting on with the eye drops. If you are someone with allergies to many of the eye drop preparations, this might offer you an opportunity to gain some relief. I will approach the Blood Donor Department at Addenbrooke's to find out if this is a realistic option for our members and will give you contact details in a future newsletter.

There was also an interesting book review by their member Terri H, which he thinks all ‘ANers’ should read, especially those of us with facial problems. The book is called **“Hell in the Head”** and is written by **David Douglas Shannon**, who used to be an actor and appeared in the TV series *House*, and various films including *The Bucket List* and *The Artist*. Terri found this book to be immensely readable and uplifting. In his book, David Douglas Shannon details his diagnosis, treatment and recovery, his ups and downs, and the things that made the most impression on him. He talks about some of the issues that many of us face, like the muzzy scrambled head after concentrating too hard on something for too long, bad balance in the dark and taste disturbance. Terri had just finished reading the book and said, in his report, that “it is such a relief to know it is real and I am not imagining it”. [This struck me as something I will try and get through the library and I thought it might also be helpful to you. Sally Hardy, Ed.]

Forthcoming Meetings

Our **Spring Meeting** will be on **Saturday 5th April, 2014** and our **Summer Meeting** will be on **Saturday 21st June, 2014**. Our **Autumn Meeting** will be on **Saturday 29th November, 2014** and our speaker at that meeting will be **Kate Burton**, Consultant Radiographer in Neuro-Oncology, Addenbrooke's Hospital, Cambridge. Our other speakers for 2014 are not yet confirmed.

Directory

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W. www.bana-uk.com
E. admin@bana-uk.com
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Fax. 01623 635313
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A. Oak House B, Ransomwood Park,
Southwell Road West, Mansfield, Notts,
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Meningioma UK

W. www.meningiomauk.org
E. support-enquiries@meningiomauk.org
(Patient information & support)
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(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 OTB

Cambridge Campaign for Tackling Acquired Deafness (CAMTAD)

W. www.camtadcamb.org.uk
E. 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
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

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