

# AMNET NEWS



Issue 60 Autumn 2014

## Our Summer Meeting

was held at Addenbrooke's Hospital, Cambridge on Saturday 21st June, 2014, and featured a presentation on:

### Facial Nerve Palsy

by **Mr Cornelius Rene, MBBS, FRCOphth.**

**Consultant Ophthalmic and Oculoplastic Surgeon at**

**Addenbrooke's Hospital, Cambridge and**

**Hinchingsbrooke Hospital, Huntingdon.**



Many thanks Mr Rene, from all members present – we found your talk really informative and helpful. A full account of this presentation can be seen on page 2.

### Important news re PARKING at

**Addenbrooke's** and how this might affect you when attending our Members' Meetings. Please see page 6 for further details.



We were very sad to hear the news that our centenarian member, Arthur Davis died recently; he didn't quite make it to 101! Further details, and a comment from Mr Moffat can be found on page 11.



Great news about the new logo for BANA and their Big Lottery Fund grant which has enabled them to redevelop their website. See the article by Debra Nash, Chief Executive of BANA on page 4.

## Our Next Meeting

Will be on **Saturday 22nd November, 2014** in the Boardroom at Addenbrooke's Hospital, Cambridge. This is our **Christmas Meeting**, so doors will open at 12.00 and you are welcome to bring a plate of food to share. This will be followed at 13.15 by a talk from **Kate Burton**, Consultant Radiographer in Neuro-Oncology at Addenbrooke's Hospital.

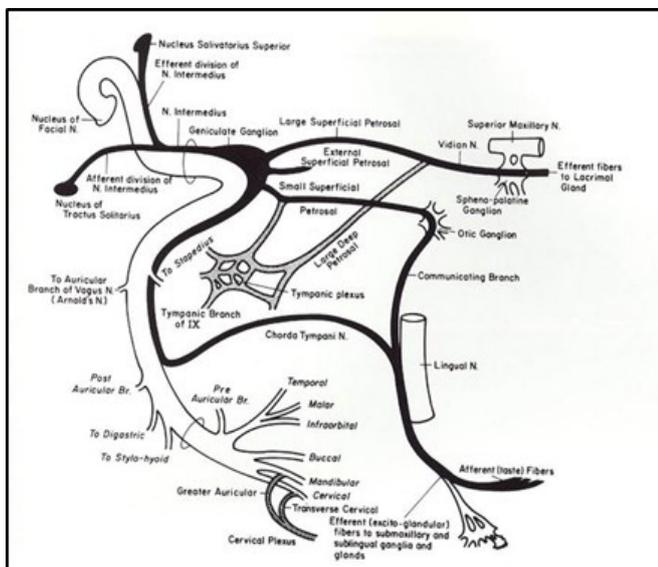
**Presentation on Facial Nerve Palsy by Mr Cornelius Rene given to AMNET members at our meeting on 21st June, 2014 in the Boardroom at Addenbrooke's Hospital, Cambridge.**

Mr Cornelius Rene kindly gave up his Saturday afternoon to come and talk to us, and introduced himself by explaining that his NHS practice operates on a 50/50 basis between Addenbrooke's Hospital, Cambridge and Hinchingsbrooke Hospital, Huntingdon. He is happy to see patients referred by their GP or other medical practitioners at either site.

Mr Rene talked about the anatomy, causes, assessment, management and surgery available for facial nerve palsy, and has kindly sent me a copy of his PowerPoint Presentation, on which this account is based.

**Anatomy of the facial nerve**

The facial nerve supplies all the muscles of facial expression. It has a long and complicated course which takes it from the brain stem, through the middle ear, emerging from the skull behind the angle of the jaw bone. It also carries nerve fibres which supply the minor salivary glands and lacrimal (tear) glands. The facial nerve and hearing/balance nerve are close together in the brain stem, hence the reason why a tumour of the hearing/balance nerve (vestibular schwannoma) often affects the facial



**Facial Nerve Anatomy**

In this diagram the main nerve is white and the associated nerve fibres to the tear gland and minor salivary glands are shown in black. (For a **larger view** of this diagram go to p. 11).

nerve. The exact location of a lesion will have a bearing on the severity of dry eye experienced by the patient. If the nerve fibres to the tear gland are involved in a facial nerve palsy, tear production is impaired, which exacerbates the dry eye.

After leaving the skull, the main trunk of the nerve enters the parotid gland (main salivary gland in the cheek) and divides into upper and lower branches. Further subdivision occurs in a very variable fashion, with much intermingling. This is the basis of aberrant regeneration.

**Causes of Facial Nerve Palsy**

Investigation is usually advised if facial nerve palsy is not improving in 2 to 3 months. Causes for this condition are varied and include:

- Rarely present from birth due to trauma caused by forceps delivery or developmental anomalies (including Möbius syndrome)
- Bell's palsy – a diagnosis of exclusion, where no other cause is obvious
- Trauma (e.g. head injury, surgery)
- Tumours (parotid gland, brain stem – including vestibular schwannoma, metastases)
- Vascular lesions or swellings (arterio-venous malformations, aneurysms)
- Stroke
- Infection e.g. middle ear infection; Shingles (Ramsay-Hunt syndrome); Lyme disease
- Inflammation e.g. Guillain-Barré syndrome; Sarcoidosis
- Cholesteotoma

**House Grading**

This is a system of assessing density of facial nerve palsy and allows fairly accurate prognosis of recovery especially when used with EMG (electrical stimulation of the nerve).

- **Grade I** Normal symmetrical facial function
- **Grade II** Mild dysfunction. Slight weakness noticeable only on close inspection. Complete eye closure with minimal effort. Slight asymmetry of smile
- **Grade III** Obvious weakness, but not disfiguring. Incomplete eye closure with minimal effort. Complete eye closure with maximal effort. Weak or absent brow movement. Mouth movement asymmetric and slightly weak.

- **Grade IV** Obvious disfiguring weakness. Unable to lift brow. Incomplete eye closure with maximal effort. Weak asymmetric mouth movement with effort.
- **Grade V** Barely perceptible movement. Incomplete eye closure. No forehead movement. Slight movement of corner of mouth.
- **Grade VI** Complete paralysis. No movement or tone. Incomplete eye closure with maximal effort.

### Main Ophthalmic Problems

- Corneal exposure caused by incomplete eyelid closure; sagging lower lid or poor blink ability.
- Watery eye.
- Cosmetic concerns, which include: brow droop; poor blink; eyelids too far apart; sagging lower lid; upper lid retraction – due to the eyelid lifting muscle being unopposed.

### Eye Assessment

During a consultation with an oculoplastic surgeon like Mr Rene, the following features would be assessed:

- The opening between the upper and lower lids
- Upper lid position
- Lower lid position
- Lower lid laxity
- Eyelid closure
- Corneal exposure
- Corneal sensation
- Bell's phenomenon – where the eyeball should roll upwards with sleep or eye closure
- Brow position

### Corneal exposure

Following treatment for a vestibular schwannoma, whether by surgery, radiotherapy or radiosurgery, a patient *may* experience dry eye syndrome and it is essential to be aware of potential problems that this could result in. Mr Rene emphasized the importance of keeping the eye well lubricated to provide corneal protection. Problems to be aware of include: **redness, pain, drying or ulceration of cornea** due to incomplete eyelid closure, poor blink and sagging of the lower lid (paralytic ectropion). Corneal drying may be exacerbated by reduced tear

secretion and poor Bell's phenomenon. The main aim of treatment is to keep the cornea moist and well protected from continued exposure.

*[From my own experience, having gone to see my GP with a very painful dry and red eye, I was seen at Addenbrooke's at an emergency Eye Clinic on the same day. Ed ]*.

Management of corneal exposure should start as soon as possible and involves frequent lubricants (drops, gels, ointment); creating a moist chamber around the eye; nocturnal taping (padding may abrade cornea); temporary eyelid weights; cyanoacrylate glue; administration of Botulinum toxin or surgery.

### Eyelid Rehabilitation Surgery

Mr Rene stressed that it was important to await recovery, if possible. Early surgery may be necessary if the cornea is threatened, especially if the recovery of facial nerve function is unlikely. Depending on the individual patient, surgical options which might be needed include: providing lower lid support to correct droopy lower lid; narrowing the wide eyelid opening; upper lid lowering; raising the lower lid; stitching the eyelids together (tarsorrhaphy); mid-face lift; and facial reanimation procedures, e.g. hypoglossal-facial anastomosis, temporalis muscle transfer.

### Upper Lid Weights

These can either be stuck on skin (tantalum) or inserted inside the upper eyelid (gold or platinum). The effect of upper lid weights should enable passive closure of upper lid and enhanced blink due to effect of gravity in erect position. Gold weight complications can include: infection; inflammation; foreign body reaction; droopy eyelid; migration of the weight; extrusion (where the weight comes out through the lid); poor cosmetic appearance or the eyelids may not close when lying flat at night especially if weight placed too high.

### Brow Droop

For those unfortunate to experience this condition, it can result in: brow ache or obscured vision. Surgical options to treat this condition involve a brow lift – using either a direct; trans-lid or endoscopic technique. However, a potential problem of brow lift is that it may exacerbate corneal exposure.

**Presentation on Facial Nerve Palsy by Mr Cornelius Rene** continued from page 3.

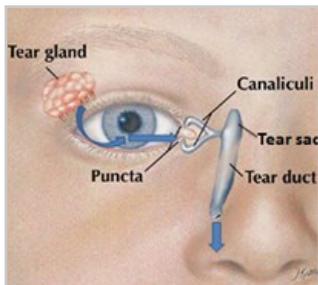
News from **BANA** from Debra Nash, Chief Executive

**Aberrant Regeneration**

When the facial nerve regenerates the nerve fibres can lose their way and grow to the wrong part of the face, e.g. fibres destined for lower face end up in eye-closing muscle. This may result in aberrant movements such as eye closing when smiling or eating. Aberrant regeneration also results in eye watering when eating or even at the sight or thought of food (crocodile tears). Use of botulinum toxin can be helpful to weaken the affected muscle.

**Watery Eye**

This is usually due to a failure to pump tears through tear duct, due to the weakness of the eyelids. It can also result from lower lid droop; can be paradoxical 2°; to excessive drying of the eye, or crocodile tears due to aberrant regeneration – often experienced when eating, and can be treated with botulinum toxin injection into the tear gland. If there is a failure to pump tears through the tear duct, a Lester Jones tube (hollow glass tube) may be required to bypass the tear duct and transmit tears from the eye to the nose .



**Tear drainage.** Tears produced by the tear gland are pumped by the eyelids through the tear duct and drain into the nose.

Following a most informative talk, Mr Rene then answered questions from those members present. We all agreed that we had learned a lot from his presentation and explanation, even those who had received treatment 20 years ago and more! Hopefully, this report will be helpful to many of our members who were unable to be present at the meeting. We particularly found that the section on Aberrant Regeneration helped account for many unusual symptoms experienced in post-surgical recovery and healing.

*[For those who may be interested, Mr Rene is also happy to see patients on a private basis. Ed]*

BANA (British Acoustic Neuroma Association) were extremely pleased to announce in July the news of a Big Lottery Fund grant to redevelop the charity’s website. The grant of £9,840 covers the cost of a brand new website, including hosting and re-branding of BANA’s logo and image, and has come at just the right time for the charity’s new phase of development which started at the end of last year.



A principal aspect of the grant is to enable BANA to reach out to more people more effectively. The application considered the ways people access the internet these days, on smart phones and tablet computers, and took into account the effects of the condition that can make it difficult for some to spend long periods of time online, such as headaches and vertigo. Members had been canvassed over the year for feedback about the previous site and the suggestions were all taken on board. The new site will therefore be more streamlined and easier to search and view. The members’ forum will include a number of new advancements to enable better interaction, and the site’s content will also be updated.

The face-lift of the BANA image includes a new logo, which has been designed in-house by the Impulse Media team who have been commissioned to complete the full website project. The design is highly individual based on the team’s visual interpretation of what they heard BANA stood for, with the circular emblem representing the community supportive spirit the charity represents.



It is hoped that the new improved website will attract more regular members to reinforce the community interaction that is so beneficial to helping people on their acoustic neuroma pathway, particularly at the point of diagnosis or treatment decision. The launch of the website will be sometime during the end of Summer 2014.

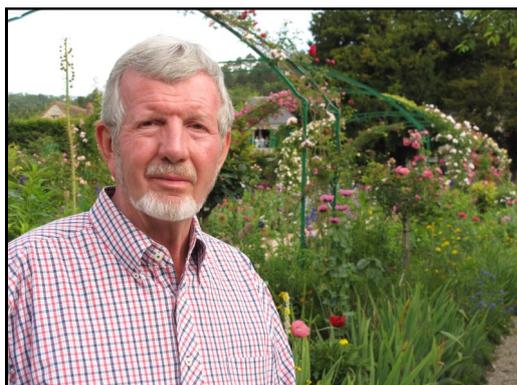
The BANA team says it is indebted to the Big Lottery Fund for making this happen for the charity and everyone it represents.

**Debra Nash** *Chief Executive*

**British Acoustic Neuroma Association**

Tapton Park Innovation Centre, Brimington Road, Tapton, Chesterfield, Derbyshire. S41 0TZ  
 Telephone: **01246 550011 & 01623 632143**  
 Website: [www.bana-uk.com](http://www.bana-uk.com)  
 Registered Charity No: 1024443

**Progress by AMNET member**



**“So Far, So Very Good”  
 by Peter Otley**

A little over three years ago, my story recounting my experience of Gamma Knife treatment was published in *Headline News* (January 2010). In 2004, at the age of 62, I'd been diagnosed with an 8mm acoustic neuroma (AN), and was monitored by 'watch, wait and rescan' until 2008 - when significant growth, to nearly 20mm, was then noticed. Treatment was advised and following discussion and study of the literature on ANs etc., I decided on treatment by Gamma Knife, which took place that summer, and a scan the following year showed a significant reduction in size.

Scans in 2010 and 2011 showed little change, the tumour remained stable and no regrowth was identified, and my latest in 2013 showed a further small reduction in size. Addenbrooke's and I were reassured that the tumour remained stable with no significant change.

Post treatment, I have not experienced any further significant side effects. My hearing – all but lost in

the left ear even prior to treatment – remains at a similar level, and the symptoms of light-headedness and tinnitus are certainly no worse now than prior to treatment. My everyday life has pretty well fully adjusted. Nevertheless, I am reassured that I can always refer myself back to the hospital should further adverse symptoms occur. Based on this post-treatment record, Addenbrooke's do not consider it necessary to undertake a further scan until 2018 - so far, so very good I say, and a big thank you goes to all concerned.

My own experience apart, given the growing numbers of ANs treated by Gamma and/or radiotherapy, members may be interested in:

**Addenbrooke's current policy on further scanning post treatment.**

They state that:

“scanning intervals are part of a standardised protocol for patients being followed after radiotherapy/Gamma (RT) for an AN. Changes in the apparent size and appearance of tumours is observed for up to two years post RT, and these will typically settle down with time. Thus scanning to five years allows Addenbrooke's to be confident that any post radiotherapy/Gamma changes have settled down. The risk of recurrence of the AN falls with time, and it is therefore a conditional probability if a patient makes it to five years post RT with no signs of tumour regrowth, then the chances of tumour regrowth in the next five years are small (less than 5% in Addenbrooke's experience). For this reason they are comfortable leaving the scans for a further five years until 10 years after RT if a patient's condition remains otherwise stable”.\*\*

Mine is now almost a 10 year story. Worrying at first but with the care and treatment described above and the reassurance provided by so many BANA members, this 'irritating little thing in my head' has not stopped me getting on with my life. Hopefully, this will be true for others who are similarly diagnosed.

\*\*Policy statement confirmed by Addenbrooke's and permission to publish authorised by Dr. Rajesh Jena

[*Many thanks for your article Peter and for the interesting and relevant scanning policy. Ed*]

## Car Parking at Ad-denbrooke's Hospital for AMNET Meetings



When the second multi-storey car park at the Ad-denbrooke's Hospital site opened recently there was a change in the car park management, and this has led to a number of changes to concessionary parking for user groups. Our Chairman, Alison Frank, has been in contact with Kath at National Car Parks about how this will affect AMNET members using car parking facilities on Saturdays, when attending meetings at the hospital. Alison has asked that we express our gratitude, here in the Newsletter, to Kath for her helpful reply, which is detailed below. *"I am happy to provide your attendees with the tickets for all of your events. If you could provide the following information in your newsletter it would be appreciated:*

- **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.

**Many thanks to Kath at National Car Parks from us all at AMNET.** It is therefore vital that you park in Car Park 1 if you would like to receive

concessionary parking and that you follow the procedure detailed here. **Until now, Car Park 1 has been referred to as "Main Hospital Car Park"** on site maps, and is probably where many of you have parked. If you are new to parking at the site, and have mobility problems, there are wheelchairs available within this car park, should this be of interest to you. It is only a 5-minute walk from Car Park 1 to the Board Room, where we hold our meetings.

## Update on Disabled Person's Railcard



At our AGM in June this year, one of our members approached me and asked whether it was necessary to be accompanied by someone (carer or not) to validate your **Disabled Person's Railcard**. As I didn't know the answer, I checked with one of our AMNET members who travels frequently by train and uses her **Disabled Person's Railcard** and the answer is no, *it is not necessary to be accompanied.*

For those who may be new to AMNET News, you might qualify for a **Disabled Person's Railcard** if you have: a visual impairment, a hearing impairment, have epilepsy or are in receipt of a disability-related benefit. To gain a card, you should first register with your local Social Services as disabled. Our member, Fiona Pike, told us previously (AMNET News, Issue 57) how she was able to complete an on-line form with her local council and received a **Disabled Person's Card** a few days later. The next step is to contact:

### Disabled persons railcard

[www.disabledpersons-railcard.co.uk](http://www.disabledpersons-railcard.co.uk)

or Telephone National Rail: 08457 48 49 50 – open 24 hours a day, and ask for a form to be sent to you.

They cost £20 for one year and £54 for three years and the advantage over a senior railcard is that you can be accompanied by someone of any age at the same rate.

**AMNET AGM** held on Saturday 21<sup>st</sup> June 2014  
in the Boardroom at Addenbrooke's Hospital.

**Apologies:** Apologies and proxy forms were received from 8 members.

**Minutes of last meeting:** were published in Issue 57, Autumn 2013, 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.

**Welcome:** Alison welcomed all those present. 18 members plus partners attended the meeting on this occasion. The parking management has changed since Addenbrooke's built a second multi-story car park, and is now managed by NCP Vinchy. On this one occasion members were allowed to park in Car Park H, so Alison wanted members to have the chance to move their cars, if necessary. In future it is possible that we may not have the option of free or reduced-price parking as a charity for our meetings on Saturdays. This is of concern and a matter that Alison and the Committee will pursue and keep members up to date about. Alison also announced that we were holding a raffle during this meeting.

**Chairman's Report:** (See page 8).

**Treasurer's Report:** (See page 8).

**Election of officers:** (See page 8).

**Changes to Constitution:** Our Acting Secretary, Chris Richards, discussed the need to review the purposes of the organisation to accommodate how we spend money that has been raised, in particular how to support those who use Clinic 10 and the Skull-Base services within Addenbrooke's Hospital, by providing limited bursaries to staff working in that department, so the 1998 Constitution needed to be reviewed. The Charity Commission no longer require charities with an income under £5,000 to be registered. As we are already registered with the Charity Commission, we have decided to remain so, even though our income is not over £5,000. We have produced a simpler edition of the Constitution and this was available for all those present to review and comment on. Chris invited members to read this document and suggested that we re-convene to elect for adoption of this new revised Constitution, which hopefully will be easier to read and understand. A change in the Constitution now states that **all** Committee members will be **Trustees**. Proposed by Heidi Pratchett and seconded by Helen Bush.

**Any Other Business:**

**Waitrose** – Mick Clothier has had a look to see nearest branches of Waitrose to where our members live. It is hoped that AMNET can be a named charity with a branch/branches of Waitrose for the green tokens issued to shoppers after completion of their shopping. To start with Bronwyn will try Ipswich to see whether this branch could help us, or if this needs to be done centrally.

**Changed venue for meetings** – Alison suggested that we consider the possibility of a changed venue for meetings, especially if parking charges become an issue for our members. She suggested Shelford Garden Centre (Scotsdale) as they have a charity room with free parking which is currently used by a number of charities. The Committee will meet and visit this venue and report back to members in a subsequent Newsletter.

**Future AGMs** – Alison suggested that future AGMs could be held in July to space out meetings throughout the year and to give more time for Newsletter production between the Spring and Summer meetings.

**Thanks** – Helen Bush thanked Sally Hardy for her input into the production of the Newsletter and Rachel Pearson thanked Alison Frank for her continued leadership in our charity.

**The meeting finished at 13.45** and there was a slight delay with our speaker, Mr Rene, as he had been operating at Hinchingsbrooke Hospital. This gave members time to read the revised Constitution.

Details of the planned changes to the "purposes for AMNET" in our new Charity Commission-based Constitution were printed and circulated to all members in our previous Newsletter (Issue 59, Summer 2014). These planned changes were available during the AGM for members to comment on. There were no objections to the changes sent to Alison Frank by proxy before the AGM and no comments or objections raised either during or after the AGM, so the new AMNET Constitution will be signed by Committee

### **Election of Officers and Committee**

Following a proposal by Andrew Hastings, Peter Otley and Alan Gosling, the following were elected en bloc:

Chairman:	Alison Frank
Treasurer:	Carol Clothier
Secretary:	Heidi Pratchett
Newsletter editor:	Sally Hardy
Publicity and promotion:	Chris Richards
General members:	Bronwyn Lummis, Charlie Lummis, Mick Clothier

Members and will be effective from the date of the AGM - 21st June, 2014.

### **Chairman's Report**

Welcome to the beginning of AMNET's 18<sup>th</sup> year. This has been a year of consolidation as Sally and Carol expand their roles as Newsletter Editor and Treasurer. We are grateful to both of them for taking on these tasks and producing excellent results. Sally has also taken on a liaison role as a Patient Representative with Ali Parkes on the East of England Anglia Cancer Network and attended the last meeting in May. Our thanks go to John Peartree, who has stood down as Secretary and from the Committee, with Chris Richards temporarily filling the gap most ably until we could find a replacement. Fortunately, Heidi Pratchett has been nominated and we welcome her to the Committee. Janice Pettitt is also standing down and we shall miss her input at Committee Meetings – not least because she takes the Minutes! Our thanks also go to other members of the Committee, working away in the background and at meetings – Bronwyn and Charlie Lummis and Mick Clothier. Neither Carol Palmer nor Rachel Pearson is on the Committee, but help behind the scenes with Newsletter distribution and as membership secretary respectively.

AMNET has again had varied speakers during the year, including Helen Hewlett, Senior Neuro-physiotherapist, Mr Neil Donnelly, Skull-base Surgeon and Brian Moore, Professor of Auditory Perception. We thank them for their input to our members' knowledge.

Last Autumn we had a training day for those helping new members. Thanks to Chris Richards for her input and to those members who attended.

Long term member, Arthur Davis, was featured on the cover of Issue 57, Autumn 2013 celebrating his 100<sup>th</sup> Birthday. He was delighted to be featured with his cake and card from the Queen. Sadly, we have recently had a phone call from his daughter to say he had died, but through the article and the photo we were all able to share his special day.

I would like to finish by thanking everyone who has helped AMNET during the year by giving time, help or donations.

Best wishes, Alison Frank.

### **Treasurer's Report**

As Carol Clothier was unable to attend this AGM, Alison discussed the Income and Expenditure Accounts for the year to 31 January 2014, prepared and signed by Carol and audited by Gilberts, Chartered Accountants, from St. Albans. A small net surplus of £203.18, is good, but indicates that we need to consider the possibility of fundraising. Our current balance in the bank is £5,596.29. Alison then read a report from Carol, stating "in 2013 we received a donation of £1500 due to the fundraising of one of our members. In 2014 we are grateful to those who made donations over and above their membership subscription of £15, and for donations given to AMNET by non-members. Our limited overheads as shown in the accounts, are due to the fact that our speakers give their very valuable time free of charge and the loyal and hardworking Committee, who not only give their time freely, but also rarely claim expenses. On your behalf, and mine, I would like to thank them for helping me to show a balance at year end in the **black!** Lastly, my personal thanks to Rachel Pearson, who is our membership secretary, and gives me great support, particularly at the January and June membership renewal times. If any member has any queries regarding the accounts, please do not hesitate to contact me."

It was proposed by Rachel Pearson and seconded by Brian Bagnall to accept these accounts.

## Fundraising

We held a raffle at our AGM and are pleased to say that this raised £26. Our grateful thanks go to Bronwyn and Charlie Lummis for organising this and well done to the lucky prize-winners.



During the month of November 2014 AMNET has been nominated as one of three local charities to benefit from the “green token system” for the “*Community Matters*” box which is operated by the check-out in **Waitrose** stores. The Cambridge Store, which is located in Trumpington, (on the right of the traffic lights at the Shelford Road junction as you leave Cambridge), is the store where we will be featured. If you shop at **Waitrose**, or know of others that do so, please ask them to consider us with their green token, on completion of their shopping trip to the store.

We wish to thank Janice Pettitt, our former Committee Member, for managing this opportunity for AMNET. Many thanks are also due to the AMNET Committee, and your daughter Chris, for getting the wording right about our charity information for the **Waitrose Community Matter** box. We will let you know about the success of this opportunity in a forthcoming edition of the Newsletter.

For those of you who are unaware of this scheme, I have looked on the **Waitrose** website for details of how this system works. If you would like to view this yourself, or for details of how this works for “online” shopping, please go to:

[www.waitrose.com/content/waitrose/en/home/inspiration/community\\_matters.html](http://www.waitrose.com/content/waitrose/en/home/inspiration/community_matters.html)

### Waitrose Community Matters We support good causes You decide who gets what

By placing a token in the Community Matters box at your local branch you're helping your community. Since its launch in 2008, the scheme has donated £14 million to local charities chosen by you.

At the end of your shop in branch, you'll receive a token to place in a box of the good cause you'd most like to support. The more tokens a cause gets, the bigger the donation they receive. Each month every Waitrose branch donates £1,000 (£500 in Convenience shops) between 3 local good causes that you choose.

## Patient Representative News

For those of you who were not present at the AGM, our Patient Representatives, (Sally Hardy and Alison Parkes), who represent patients using the Skull Base services of Clinic 10, spoke about items that are relevant to AMNET members. The East of England Cancer Network Meetings are held twice-yearly and are attended by all the clinical staff in the Skull Base Team at Addenbrooke's Hospital Cambridge, with video links to other hospitals across the Eastern Region.

During the past year we have been involved in updating the “Patient Information” booklet given to patients who are newly diagnosed with vestibular schwannomas or other skull based tumours at Addenbrooke's. We will also be involved in a Patient Satisfaction Questionnaire about the Clinic 10 services experienced by patients with skull based tumours, which is required to ensure service improvement, if necessary. The Questionnaire is still at a developmental stage.

At the last meeting, held in June 2014, Mr Richard Price did a presentation about the work he does to support facial palsy and the need for him to be accommodated within the multi-disciplinary team attending the joint clinics run by the Skull Base Team. This does not happen at present, so there is a lack of continuity for patients who require referrals to the plastic surgeons. Facial palsy treatment currently presents funding issues, as this clinical problem is not confined to vestibular schwannoma or other skull base tumours. The inclusion of Mr Price within the multidisciplinary joint clinics run by the Skull Base Team would require funding, which is not currently available. It was suggested that a letter from a patient-user organisation like AMNET, might be helpful in a funding application about this aspect of care. The AMNET Committee discussed this issue prior to the AGM and agreed that we could draw up a letter, and possibly ask for experience and comments from members at the AGM, to provide evidence to support this letter. For your information, a letter has now been submitted to Mr Tysome, Clinical Lead of the Skull Base Team, on behalf of the AMNET Committee, AMNET members and both Skull Base Patient Representatives. We received four letters about experience and comments from members at the AGM and these have been included. We will keep you informed of any developments on this matter.

## Have you ordered your Christmas Cards yet?



If not, it is almost that time of year again, and following on from our Fundraising item, we wondered if you shop online and if you might like to consider ordering cards, or more especially Christmas cards online.

We have an account with **The Greetings Card Company**, which is an online company, which was started in 1999. It is now the UK's leading online greeting card shop and offers a service of order on line and have your cards delivered the next day, with free UK delivery on all orders. With over 3000 designs, they provide cards for all occasions, offer a hand written message service to family and friends, and personalise cards in bulk for corporate or personal use.

It is also possible to purchase your gift wrap, gift bags, ribbon and tissue paper through **The Greetings Card Company**. They offer a “**Discount or Donate?**” system whereby you can choose either to support a charity or to receive an additional 2.5% discount. If you decide to support a charity, like AMNET, they will triple your contribution, giving the charity of your choice a total royalty of 7.5%. They state that donating to charity does not affect any incentive discounts you may have accrued.

Are you interested? If so, next time you need a card for *any* occasion, be it a funny one or not, do consider visiting the link:

<http://charitycards.co.uk>

where you will find that AMNET is a listed Registered Charity.

## Editorial



What a summer! I do hope you have all been able to get out and about and enjoy all that England has to offer during our months of glorious sunshine.

For those of you who were unable to come to our AGM this summer, you missed an excellent talk from Mr Cornelius Rene about the facial nerve and what it can get up to with “aberrant regeneration” (or mis-wiring in plain English). The symptoms that he discussed and members asked about, provided answers for many of us about why our eyes may seem to water when faced with appetizing food, or why my left eye tends to close when I grip the reed on my clarinet to play it! Understanding changes and why they occur really do help us when learning to accept and adapt to our new senses. I intend to smile inwardly when I play in future, and anyone watching can kid themselves that I am winking!

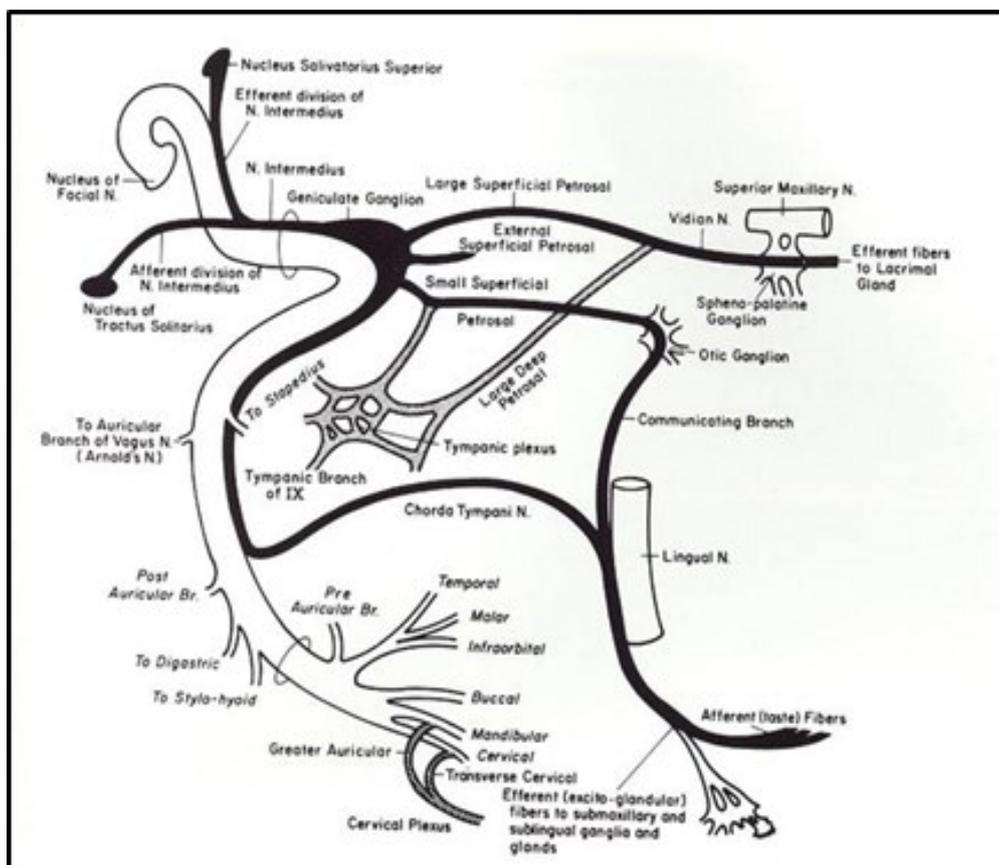
Our meeting in November will be our Christmas Meeting. On this occasion we invite members to bring along a plate of something to share and to socialize. For this reason, doors to the Boardroom at Addenbrooke's will be open from 12.00 on 22<sup>nd</sup> November, 2014. We will be holding a raffle to help raise funds, but please do not donate items for this, as we have accumulated enough. We are looking forward to welcoming Kate Burton, Consultant Radiographer in Neuro-Oncology, to talk to us after our festivities and estimate that her talk will commence at 13.15.

Sally Hardy, Editor

## Helpful Hints

Removing Lacrilube and general eye hygiene – Dilute a very small amount of baby shampoo in a clean container with warm water. With a cotton wool ball, gently wipe eyelid. It's great, gets rid of the shiny grease and is perfect general eye hygiene. If it is gentle enough for use on babies, then a little gentleness is unlikely to be harmful for us, and it is probably beneficial to keep the eyelid of a dry eye clean.

*Sally Hardy*



**An enlarged view of the diagram of the anatomy of the facial nerve,** from our report on the talk given by Mr Rene, see pages 2-4 for the remainder of the report.

**Facial Nerve Anatomy**  
 In this diagram the main nerve is white and the associated nerve fibres to the tear gland and minor salivary glands are shown in black.

**Do you remember the lovely picture of our member, Arthur Davis celebrating his 100th Birthday in Issue 57, Autumn 2013?**

Recently I heard from Janet Taylor, daughter of Arthur Davis, that Arthur had died. He sadly did not reach his 101<sup>st</sup> Birthday. In Issue 57, Autumn 2013 Edition, we told of how Arthur had surgery by Mr David Moffat and Mr David Hardy for his vestibular schwannoma 26 years ago, at the age of 75. Arthur's son, John, told me last year, that the only effect that the surgery had on his father, was that he gave up on *one* of his allotments, but carried on with his bowling!

We hope that this may give some comfort and reassurance to anyone contemplating surgery for the removal of a vestibular schwannoma, no matter what age you are.

I wrote to Mr Moffat to let him know the news of Arthur's death, and also to know how their surgical expertise had enabled Arthur to live a full and active life – *“a life lived long by enjoying good food and by keeping fit”* – that was Arthur's comment last year when asked what the secret was of living to be a centenarian.

This was the lovely reply I had from Mr Moffatt:

*“I was obviously saddened to receive your e-mail to say that Arthur Davis's family had contacted you to let us know that he had died at the amazing age of 100. Naturally his VS surgery was an important landmark in our history of surgery for acoustic neuroma in Cambridge having been at the time of the surgery the oldest patient to undergo VS excision. He was indeed an example of how modern surgery can preserve a good quality of life postoperatively for our patients and enable them to enjoy a fulfilled life after a major intracranial procedure. Obviously having established the Department of Skull Base Surgery in 1981 with David Hardy my neurosurgical colleague, it gives us a huge sense of satisfaction and pride that we have been able to develop this service over the years and there is nothing more important to us than to be able to preserve a good quality of life for our patients.”*

We conveyed our condolences, and those of Mr Moffat, to the family of Arthur Davis. They believe it would have been Arthur's wish to donate monies raised at his funeral to AMNET. These have now been gratefully received.

## Forthcoming Meetings

Our next meeting is our **Autumn Meeting** and will be on **Saturday 22nd November, 2014** (see front page for details). Our **Spring Meeting** will be held on **Saturday 18th April, 2015** and our speaker on that occasion will be **Mr James Tysome, Consultant Skull Base and Hearing Implant Surgeon and Clinical Lead of the Skull Base Team at Addenbrooke's Hospital, Cambridge**. This meeting will be held in the Board Room at Addenbrooke's Hospital - please see next Issue for details of timings.

## 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

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

CB1 3NH

### Changing Faces

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

### Facial Palsy UK

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

### Entific Medical Systems

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

### Addenbrookes Hospital

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

### Addenbrooke Hospital, Clinic 10 ENT

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

## BANA Booklets

BANA has produced some booklets which may be of interest:

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

All these booklets are available from Alison Frank The Old School House, The Green, Old Buckenham, Norfolk, NR17 1RR  
There is a £2 charge for all books.

## Necessary Note

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

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

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

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

Newsletter Editor- Sally Hardy 01954 231363

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