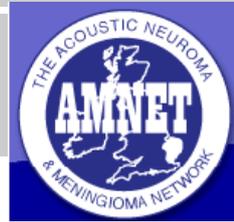


AMNET NEWS



Issue 63 Autumn 2015

Change is in the air for BANA (British Acoustic Neuroma Association) and for AMNET as we review the needs of our members.

At our **Summer 2015 Meeting** on 11th July, which was also our **AGM**, we had a change of Committee and a full report containing details can be read later in this issue. As we enter our 20th year of supporting members and their families we recognise that we need to make changes to how our charity is run and update our communication methods. We warmly welcome your response to the changes made so far and would love to hear from you about any suggestions you might like us to consider.

Over the years our charity has received tremendous support from members and their families and from a large number of health professionals and this has enabled AMNET to flourish. An example of this can be seen in a letter from Roy Kershaw (page 4).

It was very interesting, and by coincidence, that **Debra Nash**, CEO of **BANA**, came to talk to us about the changes and redevelopment that **BANA** have gone through in the last two years and about what they have in the pipeline.

Presentation by Debra Nash, Chief Executive Officer (CEO), British Acoustic Neuroma Association - BANA

on Saturday 11th July 2015 in the Boardroom at Addenbrooke's Hospital, Cambridge.



New Chairman of AMNET, Heidi Pratchett (on the left with Debra Nash)

Our Next Meeting

Will be on **Saturday 21st November, 2015** in the Boardroom at Addenbrooke's Hospital, Cambridge. This is our **Christmas Meeting**, so doors will be open at 12.00 and you are welcome to bring a plate of food to share at our Christmas social. This will be followed at 13.15 with a talk from **Joy Badcock, Lipreading Teacher** from Addenbrooke's Hospital and **Frances Dewhurst** from **Cambridgeshire Hearing Help**. Members (and their partners) will have the chance to experience the benefits they may gain from the skill of lipreading, and to learn about aids that are available to enhance hearing experience and how to access them.

Presentation by Debra Nash,
Chief Executive Officer (CEO),
British Acoustic Neuroma
Association - BANA (Continued
from front page)

For the sake of those AMNET members who were not able to be present at this meeting I have incorporated the Powerpoint Presentation given by Debra Nash with additional comments made at the meeting enclosed in square brackets [] by me. I have referred to back issues of *Headline News*, BANA's Magazine for members for details. Approval for inclusion of this material has been granted by BANA.

Debra told us that she will have been in post as CEO at BANA for 2 years this November. When she joined, BANA was undergoing a time of redevelopment. New Trustees had been recruited with a focus on developing the charity. "*The Encephalitis Society*", based in York, demonstrated to BANA's previous trustees at the time how to run a charity with a CEO and were very supportive, and following that presentation the decision was made to take on that management structure.

Current Trustees are as follows:

- Stephen Cortman – Chairman
- George Nutt – Vice Chairman/Treasurer
- Mike Maslin – Secretary
- Phil Whiley – Business Consultant
- Mr Simon Lloyd – Consultant Skull Base Surgeon

Earlier this year BANA were proud to welcome two Patrons, both eminent Cambridge medical professionals in the acoustic neuroma field, both well-known to us at AMNET - Mr David Moffat, Consultant in Otoneurological and Skull Base Surgery and Professor Brian Moore, Emeritus Professor of Auditory Perception. It is hoped that their patronage and support will assist BANA to further their charity's aims, and raise their profile as the UK's only *national* charity supporting this condition.

Other BANA office staff:

- Debra Nash – CEO
- Trish Hibbert – Accounts
- Heather Trueman – Membership Support Administrator

A pro-active approach to membership is used by staff in the office and they aim to phone back or e-mail callers after joining as they appreciate that some information given may be forgotten due to the trauma of initial diagnosis.

How it all began

In 1992 a group of patients from Queen's Medical Centre, Nottingham got together to set up the charity as volunteers. In 1998 a Lottery Fund grant enabled them to set up an office and hire a co-ordinator. As with everything in life, over time things change, communication methods change and the work of the charity is now based on considering the "person" and their individual needs.

Charity Objectives

- Assist and support people who have been diagnosed as having or who have been treated for acoustic neuroma (vestibular schwannoma), and other related conditions and others affected by such conditions
- Promote and support research and to publish the results of such research into medical, surgical and other procedures likely to lead to the prevention, early detection and successful treatment of such conditions
- Promote and support research and to publish the results of such research into medical, surgical and other procedures assisting in the rehabilitation and quality of life of people affected by such conditions

There is currently investment into these last two objectives as BANA aims to improve on this aspect of their involvement, with Mike Maslin and Simon Lloyd helping the charity to see how it may promote research within its resources.

How we meet our objectives

- Supply reliably sourced information from within the medical profession. [Debra added that this information is verified by Mr David Moffat and other prominent Consultants].
- Support mechanisms in place. [Debra elaborated that BANA booklets are no longer being sold, but are given out to those in need, and response to this change has been very grateful. New downloadable leaflets are available to

members, to help those with an acoustic neuroma by explaining the condition from the patient's perspective. Debra is a trained counsellor and is passionate in her desire to help members, as she often hears that those with an acoustic neuroma feel isolated. She commented that people have told her how angry they get when told how "lucky" they are not to have a cancerous tumour. There is now a downloadable leaflet for GP's, and members can download a copy of this and take it along to discuss with their GP. There is also a downloadable leaflet for employers, which might help with any adjustments that need to be made in the workplace. The downloadable leaflet for families and friends gives useful information about living with single-sided deafness and how, when you ask "where are you?" it is no help to hear the word "here"! For most of us the word "here" will be followed by us asking "where is here?".

- Development of community platforms for peer-to-peer interaction, information sharing and advice giving
- Ongoing supply of information and news pertinent to the condition and interrelated symptoms
- Pending - research grant call-out

The New Structure

The Board of Trustees are responsible for governance of the charity in line with the Charity Commission and the law; to determine the charity's direction; to develop strategic vision and to identify projects to meet objectives.

The CEO role is a full-time position and responsible for the management of BANA, its employees and volunteers; to inform and assist trustees in strategic focus; to action and manage projects and to maintain budget control.

The Employees are responsible for administration; provide caller assistance; signpost enquirers for support and advise and inform the CEO of any needs.

The Volunteers provide vital additional resources; local area group network and administration support.

Why is a next phase necessary?

- To improve the charity and its services
- To compete with other charities
- To change with the times
- To utilise new and better ways of working
- To ensure forward movement
- To meet Charity Commission expectations for managing charitable funds

Debra pointed out that there is a need to improve and compete with other charities and at the same time be accountable. A business perspective is needed and an awareness of what people's needs and wants are. She believes that there is a need to keep moving forward to see what more you can do for the people you are working for.

An exciting new development is the announcement that Andy Brown, lead vocalist and songwriter in pop rock band **Lawson** has become BANA's first Ambassador. Having been personally affected by an acoustic neuroma, and with his band taking their name from the surgeon who performed his surgery, it is hoped that Andy will be a perfect Ambassador for the charity and serve as a message of hope and positivity to others diagnosed with this type of brain tumour.

Redevelopment successes

- £10,000 Big Lottery Fund grant and other smaller grants [some of this has been used to redevelop the website].
- New website and charity rebranding
- Most successful financial year since the charity was formed
- Support of two eminent medical professionals in the field as Patrons
- Support of Platinum selling music artist as Ambassador
- Increase in staff resources
- Increased credence within medical fraternity

What's in the pipeline?

- Research grant call-out
- Change of Charitable Status [BANA is an unincorporated charity, which means it is recognised as a group of people working towards a common aim but in its own right it has no

legal existence; the responsibilities and legal liabilities falling to the trustees in office at any one time. The aim is to become incorporated, or a Charitable Incorporated Organisation (CIO). This would transfer the burden of liabilities to the charity itself, creating more stability and a legal structure. At the AGM at the BANA National Conference a strong majority of those present voted **for** moving BANA to CIO status].

- Video clips production [In 2000 a film entitled "Don't Panic" was made to help members with their diagnosis. As this becomes out of date it is planned to make new video clips to put on YouTube. Mr Lloyd is involved in a production about what an acoustic neuroma is. Also planned is a video clip about members' experiences and one about BANA and what they do].
- Area Group Co-ordinator – new employee role
- Development of area groups [The intention here is to connect people in their local area to achieve the aims of the Charity].

Forging change

Future aims are to provide information to help people who have problems in employment because of their symptoms, and to help people obtain benefits they may be entitled to, e.g. railcards for the hearing-impaired, as resources become available.

A brief question and answer session followed before Debra returned home. We were very grateful that she gave up her Saturday to travel to Cambridge and share this information with us.

Since the meeting we have received an update from BANA in which Debra Nash has announced that they now have a **second Ambassador** in the BANA team. **Danielle Gibbons** is a passionate footballer who plays for Liverpool Ladies and has represented England at Under 19 level. Debra states that "BANA is indebted to Danielle for the part she wishes to play in raising the profile of this rare and debilitating condition". Danielle decided to write a very personal Blog describing her acoustic neuroma journey in order to document her progress - the highs and the lows - and ultimately to give an insight into the condition prior to surgery and into her life post-surgery. I am certain this is a young lady we will hear more about from BANA in the future.

Letter from member Roy Kershaw to Carol Clothier, Treasurer

A lovely handwritten letter from Roy Kershaw to our Treasurer, Carol Clothier was received just prior to our AGM and we have been given permission by Roy to include it here for your appreciation too.

"Having received the Summer 2015 issue of AMNET News recently and noting the request for new Trustees, I thought I would write to say I can only support you from a distance due to my age and present state of health. So perhaps a few lines may help - with a review of my 25 years of experience of acoustic neuromas and the formation of the Acoustic Neuroma and Meningioma Network - along with the hope that there is support for your request from other and hopefully more able members.

My operation for an acoustic neuroma was performed in October 1991 by David Moffat and David Hardy, with initial help from David Baguley, and was a day long operation followed by intensive-care. I was happy to have had a successful operation, even allowing for the double vision that remains with me and the 50% loss of hearing.

I was also present at the inaugural meeting in the Cambridge Hotel in 1995 when, following an enjoyable lunch, David Moffat spoke about what their work involved, and also mentioned how he and Alison Frank were involved in the idea of AMNET. I am embarrassed to say that I led the applause at their announcement, though pleased to do so.

In the early days I did submit the occasional letter for inclusion in what was a rather smaller Newsletter, compared with the larger, more modern and informative version today (and very interesting).

I am now 86 years old with one (or two) other health problems, am unable to get around easily and no longer allowed to drive. So I can only wish from a distance that the AGM is successful, that some younger members of AMNET come forward to offer help and to assure a continuation of something worthwhile.

Best wishes to you and Alison Frank and Committee members and all other members.

From Roy Kershaw"

AMNET AGM held on Saturday 11th July 2015
in the Boardroom at Addenbrooke's Hospital

Apologies: 1 apology was received by Alison Frank and 5 proxy forms received from members. 17 members (plus partners/friends) were present.

Minutes of the last meeting: were published in Issue 60, Autumn 2014, 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 Minutes were signed by Alison Frank.

Welcome: Alison welcomed all those present.

Chairman's Report: Welcome to the beginning of AMNET's 19th year. This has been a further year of change as newer members of the Committee settle in and instigate new ideas. It is now the right time for me to hand over the Chairmanship to someone with fresh ideas. I am grateful to Heidi for volunteering for this role which evolves well when the Committee and helpers are working amicably together for the good of our well-loved charity. AMNET's foundations are solid, so it is a matter of building further strong extensions into the future. I will stay on the Committee and continue with some jobs to help Heidi settle in and hopefully help our future growth. Anyone with ideas for AMNET's development would be very welcome.

During the year Carol, Sally, Chris, Bronwyn, Heidi, Charlie and Mick have worked hard at their various tasks for the good of AMNET and I thank them for this. Other members who kindly help are Rachel Pearson (now Davies) as Membership Secretary and Carol Palmer with newsletter distribution, Ali Parkes, who accompanies Sally in her liaison role as Patient Representative with the East Anglia Cancer Network, involving Mr James Tysome and other Addenbrooke's staff. Thanks to all of these. Last year we hoped that AMNET could be a named charity in the green token scheme that Waitrose run in their shops. This went ahead in the Cambridge Branch in November 2014. We are grateful to member Janice Pettitt for arranging this. It also brought a phone call from a Waitrose shopper who was a patient at Addenbrooke's and wanted information about AMNET! Also last year we were worried about the changes to the parking charges here, but by liaising with the car park manager we have been allowed reduced price parking in Car Park 1, for which we are grateful. AMNET has had a variety of speakers during this year beginning with Mr Rene, Consultant Ophthalmic and Oculoplastic Surgeon last summer – telling us about treatment of facial nerve palsy and ophthalmic problems. In November we welcomed back Kate Burton, Consultant Radiographer in Neuro-Oncology, who has been a stalwart supporter of AMNET over the years and is on our Advisory Board. In Spring we heard from James Tysome, Consultant Skull Base and Hearing Implant Surgeon – detailing what the skull base service does. We are very grateful to them all for giving up their Saturday afternoons to educate and enlighten us. Next summer AMNET will be 20 years old, so we shall find ways to celebrate.

I would like to finish by thanking all the many people who have helped AMNET and me over the years in a great variety of ways with time, expertise and donations.

Alison Frank

Treasurer's Report: Accounts Year ended 31st January 2015: Good afternoon everyone. First of all, please accept my apologies for the layout of the accounts in the last Newsletter which had printing errors in it and was not well presented. We do have the Newsletter proof-read, but for some reason these problems were not picked up this time. However, I hope that you were able to make some sense of it. For correctness we are inserting the accounts again later in this issue of the Newsletter.

Re Income – our subscription revenue has remained the same, but the donations we have received are up by almost £1000. We received large donations from Ali Parkes, the family of the late Arthur Davis, Mr & Mrs Clifton, Maddie Kilgour and also Waitrose. We also received donations in addition to the membership renewal and to everyone we say a huge thank you.

Continued overleaf

Treasurer's Report (Continued from previous page)

Re Expenses – the comparison printing cost for 2014 was omitted from the Newsletter. The figure of £1387.85 should be there and you would then see that printing and postage costs are reduced year on year. This is because in 2014 we sent out a questionnaire which involved this extra cost. These two items are our main expenditure and the remaining expenses have not varied considerably.

We have, therefore, at the end of the financial year, a healthy surplus of £1371.61.

Thank you to everyone for renewing membership and continuing support of AMNET in this way and special thanks to Rachel Davies who is instrumental in sending out the membership renewals.

If anyone has any questions re the accounts, I will be happy to answer them. Carol Clothier, Treasurer.

It was proposed by Fiona Pike and seconded by Brian Bagnall to accept these accounts.

Election of Officers:

Chairman:	Heidi Pratchett	Proposed by Bronwyn Lummis Seconded by Mick Clothier
Treasurer:	Carol Clothier	Proposed by Chris Richards Seconded by Andrew Hastings
Secretary:	to be decided at a subsequent Committee Meeting	
Newsletter Editor:	Sally Hardy	
General members:	Mick Clothier, Alison Frank, Bronwyn Lummis, Charlie Lummis and Chris Richards	

Any Other Business: Heidi Pratchett gave a formal thank you to Alison Frank for all that she has done for AMNET over the past 19 years. She pointed out that we all have our own stories, but that in each case Alison has been supportive. We are all grateful and are all stronger thanks to Alison's knowledgeable dedication, commitment and drive. She will be a hard act to follow. However, we are not going to lose Alison. Instead, Alison has been offered and graciously accepted the new honorary position of President.

At this stage Alison was presented with gifts of appreciation, which included a crystal paperweight, a rose and a hand-made cake topped with the AMNET logo. Chris Richards was presented with a rose to thank her for help and legal knowledge in dealing with the Charities Commission and formalizing the Constitution.

Chris then commented that she had received correspondence from the Charities Commission about our changes to the Constitution, where they suggested one small clause: in the event of the charity ever closing down, the Charities Commission suggested that the range of who the funds are handed on to should be extended.

At the end of the AGM two new members volunteered to join the Committee. We are very pleased to welcome Stephanie and Henry Sessions and look forward to their input.



Alison Frank (on the left) receiving her gifts from Sally Hardy, Heidi Pratchett and Carol Clothier.

Message from Alison Frank

At the July AGM for the beginning of AMNET's 20th year the Committee kindly presented me with some gifts as I stood down as Chairman. These were an engraved glass paperweight shaped like a diamond and a beautiful rose named Forever Friends which is flowering for the second time (September). To top this off there was also a magnificent blue iced cake with the AMNET logo on it very skilfully made by Heidi's daughter Aimee.

As Heidi takes over as Chairman, I am honoured to become President.

After the AGM we heard from Debra Nash CEO of BANA about all the changes that their organisation has gone through over the last few years. AMNET is at the beginning of this process of major change as the Committee focuses on every aspect of our important network. By definition a network is only successful if all the elements are working together constructively. This is my hope for AMNET and part of what I envisaged all those years ago when I needed peer support and it wasn't there.

Now AMNET is established and we have forged strong links with Addenbrooke's staff and many others to assist us to help those who need us in whatever way we can in the modern world.

As retiring Chairman I wish to thank all of you - both Committee and members for my gifts and your continuing support over the years.

Best wishes
Alison.

Twenty Years On!
**Some thoughts from the past and
for the future.**
**Written by Chris Richards with in-
put from Committee members**

I would like to just thank everyone for the kind words and gift of a rose at the AGM. I have planted the rose in a prominent place in the garden and will enjoy watching it flower.

Next year will be the 20th Anniversary of the founding of AMNET - the first meeting was held in the Cambridge Hotel in Cambridge, as the guests of Mr Moffat, on June 1st 1996. The original idea for AMNET was Alison's and she took it to Mr Moffat, who felt it was important enough to support the inaugural meeting and invite all his patients. When her acoustic neuroma* (see page 8) was diagnosed Alison wanted to talk to someone who had been through the same experience, but there was no-one. My own experience mirrored this, although my nursing connections helped a little, but it was still very difficult to find out anything 'from the horse's mouth'. This was obviously in the days before you could reach the world on the internet, and people diagnosed with this type of rare cranial tumour found themselves very much alone. There were no specialist nurses and we would not have dreamed of going back to the consultant with questions.

The founding members of AMNET, who also included Joanne See, had the aim of reaching out to people who had been diagnosed with an acoustic neuroma and offering a listening ear, information and the benefit of their own experience.

Over the last twenty years much has changed in the world of acoustic neuromas and meningiomas. For a start acoustic neuroma now has a different name - vestibular schwannoma. I did not find it easy to remember 'acoustic neuroma' when I was first diagnosed, the name 'vestibular schwannoma', does not seem any easier to remember! Acoustic neuromas are now classified as skull base tumours - their position in the skull dictates the choices of management.

Management of tumours is another factor that has changed enormously in the last 20 years. When Alison and I were diagnosed, acoustic neuromas were considered rare, and were often not discovered until they were quite large. Scans, particularly MRI, were in their infancy and very few hospitals had the technology, so were only carried out when patients presented with fairly severe symptoms. In the early nineties, the only treatment available in the UK was surgery and so we were told that an operation was required, and that this would involve the loss of hearing to the affected side, and a fairly high risk of facial paralysis. The Gamma Knife was available in Scandinavia and the USA, but hadn't reached our shores by then.

As the years passed, Gamma Knife and also Fractionated Stereotactic Radiotherapy became optional treatments for those diagnosed with smaller tumours, and the development and increased availability of scanners meant that tumours were being diagnosed earlier. These smaller tumours were often felt not to be causing too many problems and the ‘watch and wait’ option also became a choice - research showing that often these type of tumours generally grow very slowly, or do not grow at all for quite long periods.

So from a situation in which there was no choice but surgery, those diagnosed today are often faced with a choice of three options - none of which have been proved to be the ‘best possible treatment’, and choice needs to be made on an individual basis, depending on the size and location of the tumour and also the individual’s situation and feelings about the benefits and risks of the different options.



Chris Richards, who wrote these kind words about Alison Frank and AMNET.

Throughout this time AMNET has endeavoured, with great thanks to Alison - who has usually been the first point of contact for those coming to the organisation - to be a listening ear and a source of information for those facing surgery in the early days, or more recently in making the difficult choice about management of their tumour.

So where is AMNET 20 years on?

These days there is a lot more support within the hospital team, where all the disciplines work together to give patients as much information as they need to make shared decisions with the team. There are surgeons, radiologists, radiotherapists and specialist

nurses, all there to listen and provide information when the patient needs it. There is also, of course, the internet which is an almost endless source of information, although navigating this to find what is useful and relevant can be a difficult and sometimes alarming journey.

The situation has changed and information is readily available to all those diagnosed with skull base tumours. However for some people who are diagnosed, it is still important to be able to talk to someone who has shared the experience and come out the other side. This is something only a self-help group can provide. There are also some people for whom the treatment is not fully successful or who are dealing with serious side effects of treatment, who find the company of others with similar issues helpful and supportive. For some people who opt for the surgical choice, they awake from surgery to find they did not have an acoustic neuroma – even with high-precision MRI scans and years of expertise it is not always possible to differentiate some skull base tumours until the surgeon has the tumour revealed, or even until afterwards when a biopsy is done. For example, for Alison, back in 1996, this revealed that her acoustic neuroma* was in fact a meningioma; for Sally, in 2011, this revealed her acoustic neuroma was a facial nerve neuroma.

Our experience, both on the Committee and throughout our extensive membership, is wide-ranging and covers a large number of years, and therefore there is likely to be someone available to listen.

AMNET does still have a role to play, but the Committee are thinking about how that role should develop in the future. The objects of the charity are focused on helping and supporting those diagnosed with skull base tumours, their family and friends, and liaising with the clinical teams – these remain central, but how do we do this?

We have built up **good relationships** with the Skull Base Team (Clinic 10) at Addenbrooke’s Hospital here in Cambridge over the years. We have “Patient Representatives” – Sally Hardy and Ali Parkes, who regularly attend East of England Cancer Network meetings and give the patient’s perspective where appropriate. We help when we can from within the charity when the Skull Base

Team need to recruit people to take part in research or surveys. We have a close relationship with BANA, the British Acoustic Neuroma Association, representing them in the East Anglian region, and also locally based groups such as Meningioma UK and Cambridgeshire Hearing Help.

In terms of providing support to members, the Committee is working on **updating the AMNET website**, so hopefully it will provide a useful resource, especially to those newly diagnosed in East Anglia, and possibly further afield.

Another consideration that is being looked at is the **format of meetings** - whether to reduce the number of larger meetings that are held in Cambridge with speakers and develop more frequent, informal and locally based meetings.

Your views on these proposals, and also any other ideas you may like to be considered are welcome.

Meanwhile the 20th Anniversary is on the horizon. It is planned for June 2016 (date to be confirmed) and we are hoping to combine some formal input with an enjoyable afternoon. Any suggestions for the format will be gratefully received – as soon as possible please! We would really love to see as many of you as possible, especially those of you who still receive the newsletter, but may no longer come to meetings regularly. This could be the opportunity for a great reunion. I know I am looking forward to it!

Help with Car Parking Expenses at Addenbrooke's Hospital, Cambridge



If you have more than one appointment at Addenbrooke's Hospital within a week a visit to the **Concessions section** at the **Customer Service Desk**, adjacent to the **exit barriers in Car Park 1** could help reduce the price you pay. You can either do this prior to going back to your car, or there is limited temporary parking near the exit to allow you to do this. Your ticket will then be validated into a **weekly ticket** and you will only pay £3.40 for as many visits as you make within that week. **Any clinic appointment** you have at Addenbrooke's entitles you to reduced charge of £3.40, but you are expected to show proof of your appointment. With this in mind, Alison Frank approached the

manager of the car parks, Kath Stirrup, and it has been agreed that **if you attend a clinic appointment in the same week as an AMNET Meeting** which is held at Addenbrooke's, that **you will be entitled to have a weekly ticket**. You should take a copy of AMNET News to the Concessions Section in Car Park 1, as mentioned above. This will have details of the AMNET meeting on the front page. It might be useful to remind you of what to do about parking when you attend an AMNET meeting, so I have reproduced this for your information.

- **Park only in CAR PARK 1**
 - Take a ticket at entry and take the ticket to the meeting with you.
 - Either Alison Frank or Heidi Pratchett needs to sign it 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.

Improving the life of your Hearing Aid Battery

The following information appeared in the latest newsletter sent out by **Cambridgeshire Hearing Help**. A young audiology patient, Ethan Manuell, from America wears one hearing aid and looked into the effect wait time has on hearing aid batteries. When activating a hearing aid battery, users remove a sticker on the battery which allows oxygen to mix with zinc-oxide inside the battery. What Ethan found was that if users wait **5 minutes** after pulling off the sticker, **the battery will last 2-3 days longer**. This is significant - considering batteries usually last anywhere from 2-7 days depending on the model. Ethan explains "The more energised zinc you have, the longer it lasts. So this discovery I made, **if you wait five minutes, it improves the battery life by 80%**" Ethan has won several awards and received recognition for his "5 minute rule" discovery, including earning a US Naval Science Award. Source: <http://kimt.com/2015/05/05/student-makes-discovery-when-it-comes-to-extending-hearing-aidbattery-life/>.

AMNET Accounts 2014 and 2015

	Year End 31 Jan 15	Year End 31 Jan 14		Year End 31 Jan 15	Year End 31 Jan 14
Income	£	£	Expenditure	£	£
Subscriptions	1700.00	1640.00	Printing	1097.25	1387.85
Donations	1446.00	477.00	Postage	472.75	610.14
Booklet Sales	23.00	21.00	Booklets/BANA	106.05	75.50
Fundraising	123.00	265.20	Website (Domain name)	30.00	30.00
Trophic Stimulators- recycle	50.00		Miscellaneous	264.51	96.74
Bank Interest	0.17	0.21			
Totals	3342.17	2403.41	Totals	1970.56	2200.23
Bank Account			Surplus for year		
Brought forward	5596.29	5393.11		1371.61	203.18
Carried forward	6967.90	5596.29			

AMNET Membership Renewals

Membership renewal letters are issued twice a year, i.e. January and June. We try to set the renewal date as near as possible to the date of joining, but in the first year of membership this could vary by a couple of months either way. Over the years we have found this to be the most economical way, both in time and cost, to send out renewals.

Postage is one of AMNET's largest overheads and it would help the funds if the renewal could be paid promptly to avoid further postal reminders. We may contact you by email or telephone to check if you wish to continue membership to avoid additional costs. We all have busy lives these days and we do not want members to feel harassed should we contact you in this way. However, we try to be efficient in the running of the charity and we do not want to send out the Newsletter if it is no longer wanted. It is also very important that we know of any changes in contact details, address, telephone and email. Thank you for your co-operation and your continued support of AMNET.

Carol Clothier Treasurer

Receiving AMNET News in PDF form via e-mail

A small number of members have approached us about receiving their Newsletter in PDF form via e-mail. To be fair to all members *we would like to offer this facility to anyone who may be interested*. This will need careful consideration and management. It will certainly save cost on postage and some members may find it easier to read the Newsletter on their computer, especially those with particular visual problems. The Newsletter will be in colour when received this way.

Have you ordered your Christmas Cards yet?



This may seem a little early, but by the time this issue is printed and distributed then we may be getting close to November, so we thought this could be relevant to you. If you shop online you might like to consider ordering cards, or more especially Christmas cards online. If you think it relevant we could consider having cards available for purchase at subsequent Autumn meetings.

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



Those of you who didn't come along to the Summer Meeting missed a real treat! We started the meeting with a light lunch, kindly sourced by Carol and Mick Clothier and Bronwyn and Charlie Lummis mixed up the most refreshing non alcoholic summer punch. It was delicious and the relaxed atmosphere gave members chance to socialize prior to our AGM.

Our next meeting is also our “Christmas Meeting”, so do please come along and, if possible, bring a plate/pack of food to share with others. This is also traditionally the meeting where we hold a raffle, so you never know what you might end up going home with.

Some of you will have had the chance to meet Frances Dewhurst (from Cambridgeshire Hearing Help – formerly CAMTAD) before, but do come along as technology is constantly being upgraded and you may see or hear about something that can make your hearing experience a more enjoyable one. Joy Badcock is fascinating in her lip-reading classes, so I know her presentation will be interesting and relevant. She has a profound hearing loss herself, which gives her real insight into the problems faced by many of us.

If, for any reason, transport is a problem for you to attend meetings, why not let us know? We have a large membership, especially throughout East Anglia, and we may know of someone else who lives near you who would gladly give you a lift or accompany you in your journey to Cambridge.

We recently reviewed our membership at a Committee Meeting and discovered that 58 current members joined AMNET prior to the year 2000. We are therefore aware that many of our members may have other health issues or find travelling to Cambridge difficult. With this in mind we are considering holding some smaller, more local meetings around our area to give more members a chance to meet up and receive support.

Sally Hardy, Editor

Forthcoming Meetings

Our 20th Anniversary Meeting is planned for June 2016. The date, speaker and location for this meeting will be announced in our next Newsletter.

Directory

AMNET

W. www.amnet-charity.org.uk
E. contact.amnet@btinternet.com
T. 01953 860692

A. The Old School House, The Green,
Old Buckenham, Norfolk, NR17 1RR

British Acoustic Neuroma Association (BANA)

W. www.bana-uk.com
E. admin@bana-uk.com
T. 01246 550011

Freephone. 0800 6523143

A. Tapton Park Innovation Centre,
Brimington Road, Tapton, Chesterfield,
Derbyshire, S41 0TZ.

Meningioma UK

W. www.meningiomauk.org
E. support-enquiries@meningioma.org
(Patient information & support)
meningioma@ellapybus.greenbee.net
(Meningioma UK)
T. 01787 374084

The Brain Tumour Charity

W. www.braintumouruk.org.uk
T. 0845 4500386

A. Brain Tumour UK, Tower House,
Latimer Park, Chesham, Bucks. HP5 1TU.

Action on Hearing Loss (RNID)

W. www.actiononhearingloss.org.uk
E. informationline@hearingloss.org.uk
T. 0808 808 0123 (Info line - Freephone)
Textline. 0808 808 9000

British Tinnitus Association

W. www.tinnitus.org.uk
E. info@tinnitus.org.uk
T. 0114 250 9933
Freephone Helpline. T 0800 018 0527

A. Ground Floor, Unit 5, Acorn Business
Park, Woodseats Close, Sheffield S8 0TB

Cambridgeshire Hearing Help (CAMTAD)

www.cambridgeshirehearinghelp.org.uk
E. enquiries@cambridgeshirehearinghelp.org.uk
T / Text / Fax. 01223 416 141
(Mon - Fri 9.30am - 12.30pm)
A. 8A Romsey Terrace, Cambridge
CB1 3NH

Changing Faces

Support for people with temporary or long
term facial disfigurement problems
W. www.changingfaces.org.uk
E. info@changingfaces.org.uk
T. 0845 4500 275

Facial Palsy UK

W. www.facialpalsy.org.uk
E. info@facialpalsy.org.uk
T. 0300 030 9333
A. PO Box 1269, Peterborough, PE1 9QN

Entific Medical Systems

Info about bone conducted hearing aids,
particularly for single sided deafness.
W. www.entific.com

Addenbrookes Hospital

Neurology & 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

Necessary Note

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

AMNET Advisory Panel at Addenbrooke's Hospital, Cambridge

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

Honorary President - Alison Frank 01953 860692. Chairman - Heidi Pratchett 01255 508070.

Treasurer - Carol Clothier 01582 529938. 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 e-mail me.