

AMNET NEWS

AMNET IS AN EASTERN COUNTIES, SELF-HELP GROUP OF FORMER AND NEW ACOUSTIC NEUROMA AND MENINGIOMA PATIENTS AND CARERS, BASED IN ADDENBROOKE'S HOSPITAL, CAMBRIDGE UK

Spring 2006
Issue 35

2006 an important year for AMNET!

Welcome to our first edition of AMNET News for 2006. This is an important year for our organisation and the committee hope that you will all be able to be part of the events we are planning.

The first reason it is important is because it will be our 10 year anniversary. For those of us who can remember our first meeting at the Royal Cambridge Hotel we have come a long way since then and AMNET has provided support to many people. This year we intend to celebrate our achievements through two meetings. On July 8th we will be hosting BANA's AGM, more

information in the newsletter, and on September 16th we will be holding our own AGM in celebration of 10 years of AMNET. We are hoping that some of the people who have helped us in the past will be able to come back and join us for the celebration. Any suggestions which you think might add to this occasion please contact one of the committee members.

Along with this celebration we need to be thinking about the future and how AMNET can best serve people with acoustic neuromas and meningiomas for the next 10 years.

AMNET Beginnings

For those of you who were not around for that first meeting of AMNET I have asked Alison Frank our chairman since the beginning and the person who was responsible for the formation of AMNET for an account of how it all began.

During 1992 my problems with blocked ears and tinnitus seemed to increase. I was a primary school teacher with 2 young children, constantly on the go and I needed to be able to hear accurately. I noticed that my balance was a bit odd too. I got my ears cleaned for the umpteenth time, my hearing improved on the right but not on the left, and my balance was still impaired. When I returned to my doctor he referred me to the Norfolk and Norwich hospital, whose consultant had a friend Mr Moffat, an ENT surgeon at Addenbrookes. Six weeks later, after an MRI scan I journeyed to see Mr Moffat who confirmed I had a benign growth on the nerve of hearing called an acoustic neuroma.

I am a positive person, so I had to concentrate on more than tumour = cancer = death, which is what the word 'tumour' conjures up. I knew I'd got a battle on my hands but with help it was winnable. The staff nurse asked if I would like to sit and talk to her for a while. I didn't then, but asked if there were any patients I could talk to. There weren't – but the seed of an idea was sown.

I got through the wait for surgery, the arrangements, going into hospital, coming home and starting to recover. During this time I was still hoping for someone to compare notes with, but instead concentrated my energies on getting better. It was also discovered my acoustic neuroma was a meningioma near the acoustic neuroma site. This was the reason for two tumours in one group.

Throughout 1995 I was returning for checkups, and asked Mr Moffat and Mr Hardy if they would 'approve' of a patients support group. I thought that a group which did not have their approval would be unworkable as we might go from 'enthusiastic amateurs' to 'interfering nuisances'.

Both the consultants were very helpful, and Mr Moffat offered to speak at – and pay for, our inaugural meeting at a hotel in Cambridge. His secretary sent out letters to the last hundred patients he had operated on, plus several medical staff from Addenbrooke's many departments and other interested parties. I wondered if anyone would respond favourably, and they did. The positive replies kept arriving. On June 1st 1996 AMNET was launched and has progressed steadily since with the help of a dedicated committee and many friends – to whom many thanks are due for AMNET's continued growth.

Ray Maw, well known to many of you, has written an article about his 'Hearing Dog' Toby which you can read inside.

Forthcoming meeting

The next meeting will be held on **Saturday 8th April 2006** in the **Boardroom at Addenbrookes Hospital**. The speaker will be Kate Burton who will speak about SRT Stereotactic Radiotherapy. Doors open at 13.00 hrs.

AMNET is a member Organisation of BANA, The British Acoustic Neuroma Association
AMNET is a registered Charity No. 1073908



AMNET Christmas meeting 2005

The Christmas meeting held at Addenbrookes on 3rd December 2005 contained the usual mix of food and entertainment but this year it was all generated from within the organisation.

The meeting started with the opportunity to complete a picture quiz compiled by Eleanor Monk. While four or five members managed to score more than twenty out of twenty five some of us found it quite challenging, although definitely fun and an opportunity to talk to other members. Lunch was an impressive spread to which everyone contributed and was enjoyed by all.

Following lunch the draw for the raffle managed to provide most people with a prize – an apology to those who missed out.

The final part of the afternoon was led by Ella Pybus.

Ella has a meningioma which she has known about for a number of years and for which she received fractionated radiotherapy in 2000. The tumour is inoperable because of the position it is in within the brain, but despite long term problems including loss of hearing and sight on one side, Ella's condition is quite stable at present. She described how the experience of having a meningioma is different from that of an acoustic neuroma as it may occur anywhere in the brain producing a variety of symptoms such as epileptic fits.

When Ella was first diagnosed she joined AMNET but soon found that her situation was different from many of the AMNET members. So having discovered little helpful information for meningioma sufferers in the UK she and her friend Caroline Batt started the Meningioma Association which has helped numerous people over the last few years. Through this Ella has become interested in other organisations which aim to help and support people with brain tumours and found Brain Tumour UK which is an

umbrella organisation bringing together small groups dedicated to supporting cancer sufferers and raising money for research. These groups have often been started by people who have lost a family member to a brain tumour. Ella pointed out that AMNET is part of a larger community of people affected by brain tumours and can contribute towards the work being carried out to support these people, some of whom have fast growing and deadly tumours.

As next year is the 10th anniversary of AMNET we should be thinking about the best ways in which we can support people with acoustic neuroma not just in East Anglia but much wider afield. We need to consider how to move the organisation forward.

The meeting then broke into groups and discussed what people had found helpful to them and how needs may be changing in the light of changes in approaches to treatment.

It was felt that there should be a big celebration to mark 10 years but also that this could mark the beginning of a new direction. Past members and other who had supported the organisation could be invited, as well as members of the team at Addenbrookes. Invitations with RSVP should be sent out with the newsletter and to others.

It would be good to talk to Mr Moffat about how we could better support patient who are in the 'watch and wait' category and how he could help us to reach these people.

Ways of raising awareness about brain tumours were also discussed and ideas such as using papers, radio, other media and high profile sufferers as well as organising local events combining members of various groups were put forward.

We would like to thank Ella for facilitating this session and also for all the work she puts into AMNET alongside her role in the Meningioma Association and over the last few months as temporary Chief Executive Officer for Brain Tumour UK.

postbag



I include a couple of letters from people who have decided not to renew their membership this time but have written to let us know how AMNET helped them.

Dear all at AMNET

I've decided not to renew my membership this year. I feel I've got 'as far as I'm going'

I'd like to thank you all sincerely for all the help and support you've given me during my recovery from a meningioma! Without AMNET I would have been 'in the dark'. It was comforting to know I wasn't alone and a one off, so to speak.

I send you all my best wishes for the future.

Yours sincerely
Jennifer Wright

Dear Joanne

In many ways it is with a heavy heart that I am not renewing my membership, but I live so far away that I cannot be a member as I would wish and I would like to be, and help out. I will always be grateful to AMNET and the care and help given.

Thank you very much
Brian Lock.

This article was sent to me by our old friend Ray Maw who is now living in Ireland and felt it would be of interest to any members having major hearing problems.

My Wonderful Dog

My wonderful dog is a 'Hearing Dog', the first in the Republic of Ireland. I never thought of having a 'Hearing Dog' or any dog for that matter. However when I chose to move to an isolated spot in South West Ireland on the lower slopes of the Shehey Mountains where I would be living alone about half a mile from my son and his family, it was Ella who suggested it would be a good idea to have a 'Hearing Dog'.

Like many of you I have no hearing in my AN ear and, following in my mothers footsteps, I was gradually losing my hearing in my so-called 'good ear'. Ella's suggestion made a lot of sense to me and she very kindly contacted 'Hearing Dogs for Deaf People' for me. Shortly after my arrival in Ireland, an assessor came to visit me and recommend that I should be offered a hearing dog. Two months later, much sooner than I had expected I was invited over to 'The Grange' in Princes Risborough to meet my dog and to stay with him until I was instructed on how to respond to him. Immediately upon my arrival there I was introduced to Toby, a beautiful cocker spaniel, by his trainer. I knew then that I had made a good decision and that I was extremely lucky to be offered such a wonderful dog. Jenny, the trainer, and all the staff were so kind and helpful. I stayed in a lovely cottage and had super meals in their restaurant – all free! I was totally spoiled and enjoyed every minute of my stay.

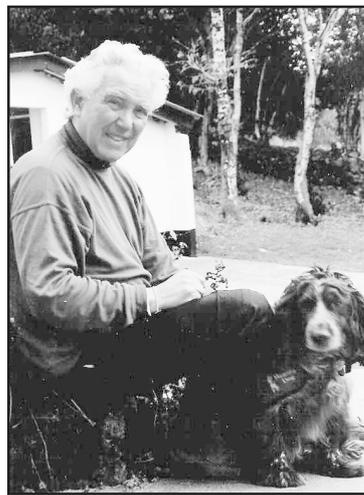
Toby had had four months training and wakes me when my alarm goes off in the morning by jumping on my bed. If I don't get up he 'bashes' me on the head with his paw until I do. He touches my leg with his paw when the telephone rings, someone is at the door, or something is going on outside. Upon asking 'What is it?' he leads me to the telephone or the door. If the smoke alarm goes off, he again touches me on the leg with his paw but this time he lies flat on the floor. If I am in bed when it goes off, he jumps on my bed and makes sure I am awake then lies on the flat on the floor at the side of my bed. After each occasion he receives a 'treat' – either a biscuit, or piece of cheese or a bit of fried sausage depending upon his response, plus of course a 'Good Boy' pat on the head.

When I am indoors and he is not around, I use a squeaker and he comes immediately and rests his paw

on my knee until I give him his treat and then sits down. Outside if he wanders off, I blow my whistle and he returns as usual putting his paw on my leg. If he does not return, I blow my 'thunderer' which is a much louder whistle. If he still doesn't respond, he has gone off into my five acres of wild mountainside with its fields and delightful white water stream which he enjoys exploring and following scent trails into the neighbouring bog. I know that after one of explorations he is likely to return a few hours later looking like a mobile bramble bush!

I have just been interrupted twice by Toby: firstly, he became restive and took me to the door – there were three dogs running across my slope and the stream. Then I thought I heard shots.

Subsequently there were two large 4x4s (=32!) which turned around in my drive, so I suspect some people were out game shooting in the area; and secondly he took me to the phone to find a friend had just rung me. I wouldn't have heard either if Toby hadn't alerted me.



Ray Maw and his 'Hearing Dog' Toby.

I have had half a dozen visits here so far from 'Hearing Dog Placement Officers' to check all is satisfactory. They are very kind and helpful. Toby is excellent with his tests and always does well. The only problem has been these occasional explorations. An animal behaviourist (or whatever she is called) came to advise me what to do. Her advice included keeping him on a long lead when I take him for a walk; exercising him on a long lead in one of my fenced fields and calling or whistling him a few times with a sausage as a treat if he responds quickly; and finally just putting a short piece of string attached to his collar. This worked well and shortly afterwards he passed his final assessment. Since then, wearing his new jacket and collar, he comes everywhere with me and never runs away. Everybody loves him and he is a wonderful dog.

I am very grateful to Ella and the 'Hearing Dogs for Deaf People' and also to his socialiser who looked after him throughout his training – we keep in touch frequently by email.

It is a joy to have such a friend.

Meningioma Association UK

Ella has sent me this extract from one of her members who has kept a diary about being diagnosed and treated for a meningioma. I am sure many of you will recognise some of the experiences she describes.

An extract from Sue Hazelden's illuminating brain tumour diary

[Sue and husband, Paul, were on holiday waiting for information about recent scans]

...The neurosurgeon first called on Sunday, but had to leave a message.

I called back and left a message asking him to try again. On Wednesday, we sat overlooking the banks of the River Exe, having just had tea at a National Trust property, and I watched the boats on the river and the sea, asked my questions, and listened to the options: surgical removal, radiosurgery, or Wait and See. We agreed I would come and see him at clinic in October. But he told me there was "No Cerebral Deficit" – good news, and the words to use to DVLA to continue driving!

Gradually we started to tell people. The boys (12, 14, 17) took it in their stride. Well, they always knew there was something wrong with their Mum's brain! Most people assumed I'd want it out. And I thought I did too, although I wasn't 100% sure. The reaction I hated most was "Oh how dreadful!" Why was it so dreadful, to have a condition for which one of the valid options was "Wait and see"? So I chose whom I told, and to others just said I had some health problems being investigated.

Work were fantastically supportive. On the days when I'd gone in not quite well enough and ended up holding onto the walls after lunch I'd been packed off home and told not to come back the next day! I was generally much better now, but they knew I couldn't cope with multi-tasking the way I'd once been able to, so we worked out ways to make life easier.

October 2004 came, and husband, Paul and I headed off to Neurosurgery. The consultant was running two hours late, we found, so the receptionist said that anyone who wanted to could see his registrar instead. Two other patients were prepared to wait – one had travelled several hours to be here. Paul and I said we would see the registrar if the consultant was happy with that – we felt we knew what our options were, just wanted to talk them through.

A charming young American, the registrar showed us my brain! And there, in the bottom left corner, was the blob, 2.5 cm x 1 cm, which wasn't supposed to be there. It was true, there was no cerebral deficit, it wasn't touching anything it shouldn't have been. He was sure that it wasn't causing the deafness, or the giddiness, or the nausea, or even the exhaustion which by now meant I rarely did anything in the evenings. But he agreed that if I was going to have it out, it would be good to do it sooner rather than later, because if it grew it could become more difficult. And he also agreed that if I didn't have it out, then any recurrence or worsening of my symptoms would be blamed on the tumour.

So we said we'd have it out! And I started to ask about timescales. My eldest was by now in his final year at school, and although he's not a worrier, I wanted it out of the way before he took his A2 exams in June. "Within 6 months", I was assured. "Definitely by April."

Off we went to wait again. I prepared by thinking what I'd need for hospital and started a binge shopping spree for new pyjamas, earplugs, and 'treats. And I got more serious about losing weight – eating less, more healthily, and walking as much as I could. My son spotted 'Brain Doctors' on TV, covering the work of the hospital I was going to, and I managed to half-watch some brain surgery – all the cases were far trickier than mine, it seemed, so that helped. One cheerful chap said "One in four of the patients I see don't make it", and I turned to my son and said "It's OK, he's not MY consultant, and my tumour's much easier to deal with than this one."

I phoned each month from January onwards, and in February was told I would DEFINITELY hear by the end of March, but April was the likely date. On the last working day of March I phoned again. It was a Thursday. "Oh, I've just written you a letter." From this point that I start to become apoplectic ...

The secretary checked the letter: an operation date of Monday 11 April, but she has posted it second class because that's not too soon, is it? However, there is also an invitation to the pre-assessment clinic on Tuesday 5 April. Can I make that? As it happens, I can, and would in any case move heaven and earth to do so, but I am not impressed. Had I not phoned – apart from the fact that our post regularly goes astray – I might have discovered all this on Saturday, and come into work on Monday to throw everyone into complete panic. The extra day makes a difference to my emotional state, if it changes nothing practically.

So I was now due to go into hospital at just over a week's notice, on the first day of the school term. I already have some time off work next week, so I have 3 days handover ... I breathed deeply and tried to stay calm. I was SO glad I started buying what I needed for hospital.

At the pre-assessment clinic all seemed to go well. I'd lost a stone, so I was no longer obese – HURRAH! My heart was beating, my lungs were fine, I'd never smoked and I rarely drink. But my blood pressure was "a little on the high side". This didn't surprise me – it has been a rather stressful few days, and the next few don't look a lot better. However, the nurse asked me to get the BP checked at the surgery later in the week just to make sure all was well.

I don't remember what the reading at the hospital was, but I think it was even higher when the practice nurse took it, twice, to be on the safe side. I found the machine excruciatingly painful, and commented on this. "Yes, lots of people say that, but I've used it on myself and don't find it too bad." Well good for you dear, maybe you have a higher pain threshold than the rest of us?

I phoned in the readings and headed off to Audiology. As I walk across the hospital car park, the neurosurgery nurse called. "I've spoken to the registrar and the anaesthetist, and they do not wish to proceed with surgery on Monday. The drug dosage they will have to use to bring your BP down to a 'safe' level is very high, and they do not like the risks this poses." "So what now?" "We'd like you to get your BP checked at the surgery throughout next week, and then see your GP. As soon as your BP comes down we can re-schedule the surgery."

We agreed I'd start taking medication. I'd also booked a week off work to try and de-stress. I felt so desperate just to have the operation, get it all over with.

I found the medication brought my BP down, but it also made me feel ghastly. Even less energy than usually, terribly woozy in the afternoons, and then after 3 weeks stomach cramps and freezing cold hands and feet! The weather was cold for May, but even so, needing bedsocks felt rather extreme.

Worse, there was no news of when I might have the operation re-scheduled for. The GP kept phoning the

hospital, I kept phoning the hospital, but no-one seemed able to get an answer from the Consultant Neurosurgeon. Finally, in mid-May, my pestering paid off and he rang me. He apologised, but a number of urgent, some life-threatening, cases had been passed to him soon after my operation had been cancelled and he now did not know when he would be able to operate on me. He proposed, if I was willing, to pass my case to a colleague who had agreed in principle to operate within 6 weeks. He gave me the name, and I agreed.

I'd been warned by my church contact that this might happen, and by this stage I didn't care who operated, as long as they were competent and I got a date! But it suddenly dawned on me that I'd just been passed on to Mr One-in-Four! I laughed. At least I should improve his odds this year.

Sue was operated on for a meningioma tumour in mid-July 2005; the operation was followed by a course of radiotherapy to prevent re-growth.

The full text can be read on the www.meningiomauk.org website [words 1500 approx]

Snippets

Portable Vibrating Fire Alarm for Hotel Stays (from Norfolk Disability Information Service)

Deafgard is a portable wire free fire alarm listening device especially designed for deaf and hard of hearing people staying in hotels or other residential facilities. As such it is an adaptation that will help hoteliers comply with the Disability Discrimination Act.

The Deafgard alarm is battery powered and is acoustically triggered by the sound of a fire alarm. The unit consists of a high density strobe and a connected vibrator pad which is placed under the pillow. When the Deafgard is alerted to the fire alarm the pad under the pillow vibrates and wakes the sleeper. The activated flashing strobe and LCD provide visual indication that the fire alarm is sounding, allowing the individual to leave their room and find a place of safety. More details available on The Connevans Deaf Equipment Website at www.deafequipment.co.uk and type in 'Deafgard' into the product search

Years of loud music can cause tumours Washington | January 08, 2006 1:23:26 PM IST

A research study has discovered that people with years of repeated exposure to loud noise have an increased risk of developing a non-cancerous tumour, called acoustic neuroma, that may lead to hearing loss.

The study found that people who had been exposed to years of loud noise were on average one-and-a-half times more likely to develop this type of tumour compared to people who weren't exposed to such noise on a regular basis.

Hearing loss occurs gradually as the tumour grows slowly and presses the cranial nerve that is responsible for sensing sound and helping with balance. Symptoms of the tumour include hearing loss and tinnitus, a constant ringing in the ears. They also typically become noticeable around age 50 or older.

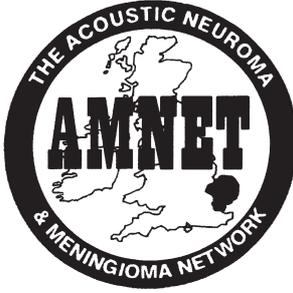
The study, by a team of researchers from Ohio State University, was led by Colin Edwards. As a part of the research, the team gathered four years of data from the Swedish portion of the INTERPHONE Study, an international study of cell phone use and tumours that affect the brain and head.

The team conducted the study on 146 study participants with acoustic neuroma, as well as an additional 564 people without the tumour who served as controls were also interviewed by a nurse. Study participants ranged in age from 20 to 69, and of the 146 people with acoustic neuroma, nearly two out of three were 50 or older.

Researchers found that the two types of loud noise posing the highest risk of acoustic neuroma development were exposure to machines, power tools and/or construction which increased tumour risk by 1.8 times and exposure to music, including employment in the music industry, which increased the risk by 2.25.

Colin Edwards said that loud noise was seen to be the cause of the tumour, and added that it did not make a difference whether it was job related or not.

"It doesn't matter if the noise comes from years of on-the-job exposure or from a source that isn't job-related. It's not surprising that the longer that people are exposed to loud noise, the greater their chances become for developing the tumour," he said. (ANI)



BANA
The British Acoustic Neuroma Association
will be holding their AGM
at Addenbrookes Hospital in Cambridge
on Saturday 8th July 2006.

The proposed programme will include:

- 10.30 Coffee
- 11.00 AGM
- 11.30 **Mr Patrick Axon FRCS** Consultant Neurotologist
 at Addenbrookes Hospital
- 12.42 Lunch
- 13.30 **Mrs Chris Richards** talking about research carried out
 with members of AMNET
- 14.00 – 15.00 **Clare Sims** Addenbrookes Superintendent Radiographer
 and a member of the Oncology team.
- 15.00 – 15.30 Tea

All BANA members and AMNET members are welcome. Please put the date in your diary.

If you don't live in East Anglia Cambridge is a beautiful place to visit in the summer – maybe you could make a weekend of it? There are a number of reasonable guest houses near the hospital and hotels in the centre of the city.

Contact:

The Cambridge Visitor Information Centre

The Old Library,
Wheeler Street,
Cambridge,
CB2 3QB.

T: 0871 226 8006. or www.visitcambridge.org

Brain Tumour UK

Ella has sent us this news release about availability of brain tumour treatments. I am sure many of you are aware of the recent controversy over treatments for breast cancer and there is a similar issue with treatments for some malignant brain tumours. This media release explains the situation and at the time of going to press there is no further information – but we will keep you updated.

Sunday, 26 February 2006

BRAIN TUMOUR PATIENTS FEAR DISCRIMINATION

UK brain tumour patient and carer groups have expressed concern that an important National Institute for Health and Clinical Excellence (NICE) meeting this Tuesday (28 Feb) might decide to make available new brain tumour therapies only on a rationed basis and will deny the therapies to patients who might otherwise benefit.

A consortium comprising Brain Tumour UK, the Samantha Dickson Research Trust and the International Brain Tumour Alliance said that the meeting of the NICE Appraisal Committee is likely to set the scene for the final guidance which NICE will convey later to the NHS.

Ella Pybus, acting Chief Executive Officer of Brain Tumour UK and spokesperson for the consortium said that NICE had flagged the concept of targeting patients one year ago.

"They mentioned sub groups and one of the eligibility criteria was to be the extent of resection. This refers to how extensively the neurosurgeon is able to cut into the brain and remove the tumour. Sometimes the tumour is in a very crucial location and this location may limit the amount of tumour that is removed. Some surgeons may also be able to remove more tumour from one patient than from another for a range of other reasons, including individual experience and skill

"In other cases only a biopsy (taking a small sample of brain tissue) might be possible and yet that person might benefit greatly from later chemotherapy and radiation therapy.

"This approach could also lead to a new postcode lottery based on a patients geographical proximity to the most skilled neurosurgeons .

"Yet another rationing technique being talked about is an age cut off to deny the therapies to older people, over 65 or 60 years, or even 50 years of age. That would be very discriminatory because wherever you draw the line there will be people excluded who might have benefited.

"None of these rationing techniques have been introduced in other countries, such as the USA, Canada, Australia, France and Germany, where the new therapies being considered by NICE have already been approved and made available," Ms Pybus said.

Contacts:

Ella Pybus

Brain Tumour UK

PO Box 94

Cumbria CA28 7WZ

Tel: 01787 374084

Email: ella.pybus@braintumouruk.org.uk

Web: www.braintumouruk.org.uk

Neil and Angela Dickson

Samantha Dickson

Research Trust (SDRT)

Century House, High Street Hartley Wintney

Hampshire RG27 8NY

Tel: 0845 130 9733

Email: SDRT1996@aol.com

Web: www.sdrt.co.uk

Kathy Oliver

International Brain Tumour Alliance (IBTA)

PO Box 244

Tadworth

Surrey

KT20 5WQ

Tel: 01737 813872

Email: kathy@theibta.org

Web: www.theibta.org

RESOURCE WEBPAGE:
www.theibta.org/NICE.htm

BANA News

BANA (British Acoustic Neuroma Association) has asked us to host their AGM this year. BANA has a number of branches and support groups around the country, some like AMNET hold regular meetings with speakers, in others members are willing to talk to people who want to know more about living with acoustic neuroma or the aftermath of treatment.

Another item in their regular Newsletter BANA Headline News is a call for sponsors for Naomi Gaffney who is running the London Marathon on behalf of BANA. This will be matched by her employers up to £500. AMNET will offer some sponsorship but if you would like to add to this please contact Julie at BANA 01623 632143 or email admin@bana-uk.com

They have also launched a new website which I will feature as an 'Interesting Websites' next time

Please think about writing something for your newsletter. It can be anything you feel will be of interest to members.

Anything from a few lines to a couple of pages

It all helps to make the newsletter more interesting.

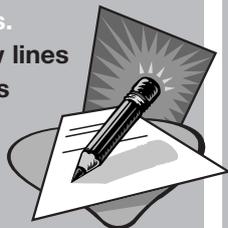
Contributions on paper and/or disc (Microsoft Word) to:-

Chris Richards

**12 Sudeley Grove, Hardwick
CAMBRIDGE CB3 7XS**

email: chris@richards2113.fsnet.co.uk

by: 26th April 2006



Next time you go surfing don't forget our AMNET web-page on <http://www.ii-group.com/amnet>

If you want to suggest any contents please let us know.

Addresses and Web sites

Addenbrooke's new website
www.addenbrooke's.org.uk

Changing Faces

(Registered Charity 1011222)

The Squire Centre,
33-37 University Street,
London WC1E 6JN

Switchboard Number: 0845 4500 275

Email: info@changingfaces.org.uk

Website <http://www.changingfaces.org.uk>

Changing Faces acts as a resource for the empowerment of people with facial distinctions. Free information packs and booklets are available.

RNID Tinnitus Helpline

(Registered Charity 207720)

Castle Cavendish Works,
Norton Street,
Nottingham NG7 5PN

Surfing the Net?



Tel/Textphone 0115 942 1520

For further information:

Email: tinnitushelpline@binternet.com

Website: <http://www.rnid.org.uk>

The British Tinnitus Association (BTA)
4th floor, White Building, Fitzalan
Square, Sheffield S1 2AZ

Freephone enquiry line 0800 018 0527

Web site: <http://www.tinnitus.org.uk/>

Hearing Concern

7-11 Armstrong Road, London W3 7JL

Help Desk 0845 0744b 600

Email: info@hearingconcern.org.uk

Web site: <http://www.hearingconcern.org.uk>

AMNET Advisory Panel at Addenbrooke's Hospital

Mr David Baguley MSc MBA
Principal Audiological Scientist

Jean Hatchell

Clinical Nurse Practitioner

Mr Robert Macfarlane MD FRCS
Consultant Neurosurgeon

Mr David Moffat BSc MA FRCS
Consultant in Otoneurological and
Skull Base Surgery

Mr N J C Sarkies MRCP FRCS
FRCOphth Consultant Ophthalmic Surgeon

The Meningioma Association UK

**53 Pine Grove,
Brookman's Park,
Herts AL9 7BL**

Tel: 01787 374084

Email: MeningiomaUK@aol.com

Website: www.meningiomaUK.org

BANA has produced some new booklets which may be of interest:-

A Basic Overview of Diagnosis and Treatment of Acoustic Neuroma

The Facial Nerve and Acoustic Neuroma

Headache after Acoustic Neuroma Surgery

Eye care after Acoustic Neuroma Surgery

Balance following Acoustic Neuroma

All these booklets are available from Alison or direct from BANA. There is a charge of £2.00 for some of them.

Facial Stimulators

AMNET has some Facial Trophic Stimulators which are available to members for short term loan. There is a charge of £25 at present which includes maintenance and postage. If you would like to know more please contact: **Margaret Allcock on 01493 700256**

BANA

**British Acoustic Neuroma Association
Oak House, Ransomwood Park
Southwell Road West
Mansfield, Notts NG21 0HJ**

Tel: 01623 632143 Fax: 01623 635313

Freephone: 0800 652 3143

Email: bana@ukan.freeseve.co.uk

New Website: www.bana-uk.com

FORTHCOMING EVENTS

DATES for your DIARY in 2006

Saturday 8th April 2006

AMNET meeting at Addenbrookes Hospital

Saturday 8th July 2006

BANA AGM in conjunction with AMNET meeting at Addenbrookes Hospital

Saturday 16th September 2006

AMNET AGM and 10 year anniversary at Addenbrookes Hospital

Saturday 25th November 2006

AMNET Christmas meeting at Addenbrookes Hospital

A 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.

Chairman

**Alison
Frank**

01953 860692

Secretary

**Tony
Monk**

01353 778423

Treasurer

**Joanne
See**

01487 814380

Newsletter Editor

**Christine
Richards**

01954 211300

New Patients
Officer

**Neil
Bray**

01223 561234

AMNET
Librarian

**Ray
Maw**

00353 23 56719