

# 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

Winter 2003  
Issue 28

## Happy Christmas and Best Wishes for the New Year to all our Members

### 'Recovering from Skull Base Surgery' AMNET Meeting held on 13th September 2003.

Our September meeting took a different form from usual. We did not have a speaker but used the meeting as an opportunity for members to talk among themselves. It was an opportunity to meet new people and to share experiences.

We started the meeting by breaking everyone up into groups, trying to ensure that couples were in different groups so people would be well mixed and each group would have both patients and carers.

The group leaders started with a question about what people would tell others who had just found out that they had a tumour. The answers were varied including telling them not to worry and comments that you do forget over time. There was quite a lot of discussion about the amount of information people want or need. There is a lot of information available on the web, but some of this is very alarming and needs to be filtered. This is difficult for patients who know little about the condition. It was acknowledged that the amount of knowledge desired is different for different people and it is important for groups like ours to provide the right amount of information at the right time. Some people talked about being frightened by the news and feeling isolated and about how they were helped by seeing and talking to someone else who had experienced the same situation. It was mentioned that GPs often don't know anything about this type of tumour so they could not be a lot of help. It was felt to be important how surgeons break the news and some patients had not found this a reassuring experience. The long wait for surgery can also be a cause of anxiety.

Members were asked what they felt had been their biggest problem following surgery. Again the answers were varied. Many people felt that problems with their face were the most difficult as it caused difficulties with eating and drinking – especially dribbling and watering of the eye when eating. It can be embarrassing in company or when you are out. Many people are left with a metallic taste in their mouth which affects appetite. Visiting the dentist can also be a problem, particularly if you are unable to open your mouth wide enough. There are also often problems with an eye which doesn't close properly. Sometimes injections, gold weights or surgery are necessary and there is often a constant need to insert drops or ointment. Finding eye drops which work and do not cause irritation has been a problem for some. Air conditioning and travelling, particularly air travel, can also present problems

Loss of balance is a problem which was frequently mentioned. This manifests itself in a feeling of vertigo which prevents activities such as climbing ladders and can even make walking on uneven ground difficult. Some people find escalators difficult and also narrow paths and stepping stones can present problems. For some this problem leads to an avoidance of open spaces and situations in which there will be crowds as they find it difficult to move quickly enough in response to other people. It is usually worse in the dark and a combination of eye and balance problems has made it difficult for some people to drive, particularly at night. Tiredness and fatigue are also a frequent problem.



### Next Meeting

Next meeting will be held on the morning of **Saturday 6th December 2003** in The David Dunn Suite at Addenbrookes Hospital. The speaker will be Mr David Moffat, Consultant in Otoneurological and Skull Base Surgery. **Please note that the doors will open at 10.30am.** As usual at Christmas we ask everyone to bring a contribution towards lunch.

Continuing pain had been a problem for some members particularly headaches and pain around the scar. For some it had taken a long time and a lot of different treatments in order to manage chronic pain. There was a feeling that more could be offered to patients with these problems and sometimes patients had to go out and find their own solutions.

Hearing loss is a problem everyone has to deal with but it is definitely exacerbated by some situations. Members reported that social situations are often difficult, sometimes to the extent of avoiding going out at all. It is difficult to keep up with what is being said in situations where there are a number of people and background noise. The other side of this is that people also find they have increased sensitivity to some sounds such as clattering cutlery. Tinnitus is also a major problem for some people.

Many members reported a loss of confidence following surgery. They found they did not go out and could not do the things they were doing before. Going back to work often presented problems and for those close to retirement

the operation often brought the date forward. There was a strong feeling of not being the same person as you were before and almost having to go through a grieving process for that loss. For some this has resulted in feelings of depression.

Partners and carers talked about some of the difficult things for them. There is a feeling of being unable to do anything especially during the surgery and immediately afterwards. In the recovery period it can be difficult, especially if the patient is suffering mood swings and feeling depressed.

There were, however, a number of positive points which people felt had helped them on the road to recovery. Many talked about the importance of talking to others who had the same problems. Setting targets to achieve helped some and activities such as physiotherapy, yoga, swimming and aqua-aerobics had all proved helpful.

This was an enjoyable session which everyone seemed to find helpful. I would like to thank the group leaders and also Jean Hatchell, Nurse Practitioner, who came along to join our sessions.

---

# Snippets

## **ENT Clinic (Clinic 10) at Addenbrookes Hospital**

(From Addenbrookes Matters September 2003)

Patients attending the ENT clinic at Addenbrooke's will get a faster and better service in future. A £1.5 million refurbishment including the installation of new and more sophisticated equipment will help staff to provide a truly patient-focused service.

The refurbishment will add two more consulting rooms, a further treatment room and two additional audiology

booths. There will also be a 'quiet room' to provide patients with some respite from the inevitable noise generated by a busy clinic.

When Clinic 10 re-opens in December 2003 it will be a state of the art facility providing patients with speedy access to what we believe will be a world class ENT and audiology service

## **Hearing the telephone**

As a result of the hospital switchboard putting a lady from BT through to me in search of someone interested in telephones for the disabled, I have acquired, totally free of charge, a loud indoor telephone ringer with a socket doubler to allow me to attach it to a phone socket. BT will provide appliances for people with hearing problems free of charge. As I obtained mine through a rather circuitous route I would suggest contacting their Customer Services department for further advice or a catalogue of equipment available.

## **Fundraising**

Grateful thanks to Peter and Dawn Holmes of Sheerness in Kent. Dawn spent many hours baking cakes for a Charity Fair in Sheerness. Selling the cakes raised £25 which they have donated to AMNET.

## **Trophic Stimulator for sale**

One of our members has a trophic stimulator which she is no longer using and wishes to sell. If you are interested please contact Margaret Allcock on 01493 700256.

# Editorial

Hello everyone

Welcome to another edition of AMNET NEWS. I hope we have an interesting selection of articles for you this time. As those of you who attended will know our September meeting took a rather different format from usual. There was no formal speaker and members themselves contributed to a discussion about their experience in small groups. I have produced a report of this which I am sure will prove interesting to those who were there as well as to those who were unable to come. I am planning to do some research next year on the experiences of people undergoing skull base surgery and I will be telling you more about it and looking for people to help me in the next issue.

As a result of attending the CAMTAD Exhibition I have found a few very useful sources of information in the newsletters and magazines of other organisations, some of which I have included in this issue. Hopefully we will be able to continue to obtain interesting and useful information in this way.

I am also pleased to have a few contributions from members. Please keep them coming and let's hear from some more of you out there.

Along with everyone else I would like to wish Ray Maw all the best in his new home in Ireland. Ray will still be pleased to provide information to members and others who require it, although maybe communication will be a little slower!

As from 2004 there will only be three issues of the newsletter each year to coincide with the meetings which will be the AGM in May, then meetings in September and December. This is hoped to reduce travelling by members in the early part of the year when the weather may be unpredictable. However we look forward to seeing as many people as possible at the December meeting which will have Mr Moffat speaking in the morning followed by the usual buffet lunch to which you all so kindly bring your contributions. I look forward to seeing you there.

Best wishes for Christmas and the New Year from all the committee.

Chris.

---

## postbag



*This letter from Pat Ford who has hearing loss and tells us about the help she received at work. Ed*

Clenchwarton, Kings Lynn

Dear Editor

I have digital aids for both ears. I had labyrinthitis 2 years ago and went deaf in one ear during the acute phase of the illness. I also lost some hearing in the other ear. It will be permanent. I was fitted with a National Health aid but it wasn't too good. Job Centre Plus (you can contact it through your local job centre) will help working people with any aid to keep them employed. It is easy to apply. Obviously if you are deaf, through a hearing aid or phone aids, but really they will be open to any suggestions if it can help your work. Your company has to agree to fund some of it. I found the local West Norfolk Society for the Deaf helpful with my application. I have top of the range Siemens aids and I didn't pay a penny, Royal Mail paid about a third and Job Centre Plus the rest. I hope this information is of help.

Yours sincerely  
Pat Ford

**I am also including an email I received from Ray Maw who is now happily settled in County Cork.**

Dear all

I'm really enjoying the peace and quiet – absolutely no sound at all except of my making. The view from the house is delightful, consisting of trees, fields and distant hills. Having unpacked nearly everything the house is now very comfortable and relaxing. Everyone around (and they are all at some distance away) are extremely friendly and have called in bearing useful gifts to welcome me. 'Daffy' the cat, (sounds better than Claudius!), loves his new home and playmates – he was left out throughout the night (by accident) and when I found him in the morning he was 'sheepishly' confronted by two beautiful nanny goats having their brekky of lilac and hydrangea. It is a rather different experience for him than life in Lavenham.

Best wishes  
Ray

# MENINGIOMA ASSOCIATION

## Planning for Recovery

---

The first time you hear you have a meningioma or an acoustic neuroma is often frightening, even though it is almost always a benign tumour.

How can you get help, support and reassurance when you need it? The consultant and your GP are the first places for information, but AMNET or The Meningioma Association UK will help with further information and support. Often this support comes from members who have been through the same experience.

**The first stage of planning** is to ask your doctor what the immediate course of action will be, say, over the next 3 to 6 months. You may be advised to have surgery, radiotherapy, or just a 'wait-and-see'. Whatever your situation, you will want to know what longer-term checks and/or scans are usually given. Following surgery and/or

radiotherapy you may have more frequent check-ups in the first year, but later it will become twice yearly and then annually. In a 'wait-and-see' situation it may be once or twice yearly, depending upon your signs and the size and location of the meningioma.

**Keep an eye on yourself** At all times, whether you are waiting for an appointment or recovering from treatment, you should be looking out for any unusual and/or new signs. The most important ones would be sight problems and fits; in that case you should immediately get in touch with your consultant and/or see your GP, who can assess you quickly. In any case, whenever you are worried you should discuss it with your GP, and he can get in touch with your consultant if necessary. Remember that the onus is on you to let your doctors know of any changes. Let them decide what is or is not important.

---

## Recovery pointers

---

### After surgery

Some general questions from people recovering from neurosurgery:

- How long will I be in hospital? Generally a week, although it obviously depends on the surgery and how you are recovering.
- Will they shave all my hair? Usually hair is only shaved from the immediate place where the incision will be. It will grow back, and in the meantime the area may be camouflaged to some extent by your other hair falling over it.
- How will I feel when I come home from the hospital? Usually you will be very tired, and this may last for quite some time. Try and arrange to have somebody at home who can help with housework, shopping and the children. How long you will feel tired varies from person to person, but by phasing yourself in gradually you will avoid getting over-tired and will re-build your strength and energy. Many people report that having two or three naps a day helped their recovery and enabled them to avoid feeling drained and tired all the time.

### After Radiotherapy

Some general questions from people recovering from radiotherapy:

- What will be happening afterwards? You will be tired for at least the first two weeks after treatment is completed. Some people feel tired for several weeks, since the effects of the radiation therapy will continue after the end of the treatment. However, this will pass, and it is not as much as you would have experienced after surgery. Any skin redness as a consequence of the treatment will usually

fade away quickly. If it is bothersome or not clearing up you should contact your radiotherapy consultant. You will be given a check-up approximately 6 weeks after the end of radiotherapy and may have another MRI scan at some time the same year. After that, MRI scans plus a follow-up consultation will normally occur on a twice-a-year or annual basis. Some acoustic neuroma patients follow a two year check-up schedule.

### During 'Wait and See'

Some general questions from people on wait-and-see:

- What is going to happen, and how do I cope? Your consultant should have discussed with you the frequency of follow-ups, including scans. Keep your appointments! If you have any change or worsening of signs, you should contact your consultant without delay. Otherwise, just get on with life and try not to think about it too much. Both AMNET and The Meningioma Association UK are there to give support.

Caroline Batt and Ella Pybus

An appendix (no, not that kind of appendix!) to Planning for Recovery

Maybe you will sympathise with the feelings expressed in this excerpt from a letter by someone still recovering from surgery:

"I'm doing very well. I was a bit fed-up a couple of weeks ago when my children had gone back to school and I was feeling a bit lonely. But I felt better last week. I think there is a feeling - as if you should be on top of the world all the time, because the operation is now over, and, of course, no-one can feel like that all the time. And you feel guilty because you have no right to be fed-up..."

# Meningioma Association UK

Congratulations to Ella and Caroline on the launch of the Meningioma Association UK Website. It is the result of much hard work and I suspect frustration. However the result is well worth it. The website has information about meningioma and how and where to find information and support. It also has links to a number of other sites, including AMNET. The website can be found at:

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

---

## Vestibular Schwannoma Conference Cambridge – July 2003

*Some of you may recall that we made quite a lot of effort to try and have a presence at this conference but were unsuccessful. We have, however, been sent a copy of the Conference Proceedings which lists short summaries of the papers and posters presented. I will endeavour to feed some of the less technical material back to you over the next couple of editions. There is a report of the conference in the Autumn 2003 Nf2 News which, with thanks to the Neurofibromatosis Association, I include below. Ed*

---

**The Fourth International Conference on Vestibular Schwannoma was held in Cambridge in July 2003. The conference was organised by Mr David Moffat (Cambridge) and Professor Richard Ramsden (Manchester).**

Previous conferences had been held in Copenhagen, Paris and Rome. At the first conference in 1991 there were just a handful of papers presented on Radiosurgery and minimal discussions on 'watch and rescan' strategies. At subsequent meetings in Paris and Rome these topics grew in interest and now in 2003, in Cambridge, they took an even more significant place in the conference programme.

In the past two years there have been important new developments in the diagnosis and treatment of vestibular schwannomas and other skull based tumours.

- The early use of MR imaging has led to the early diagnosis of vestibular schwannomas and this has led

clinicians to question whether all tumours have to be removed.

- The 'watch and rescan' policy that many centres now recommend has enabled the growth pattern of untreated tumours to be followed.
- The place of Stereotactic Radiosurgery is still controversial and was one of the most important themes of the meeting.
- Hearing preservation surgery has still not found a secure place in the management of vestibular schwannomas.
- Molecular genetics is yielding ever more information about the chromosomal abnormalities that lead to the development of vestibular schwannomas.
- The auditory brainstem implant holds promise of some useful rehabilitation of hearing after removal of tumours on the eighth nerve.

These areas and many others were explored in depth during this five day conference, with experts from around the world sharing their experience and expertise.

---

### Ray Maw

As you may have seen in the Postbag, Ray Maw has moved from Lavenham in Suffolk to County Cork. Many of you will have had contact with Ray over the years, either through the comprehensive information he has provided to anyone who asks and or by filling in his questionnaires which have provided us with essential information enabling us to find the information most appropriate for our members. Ray has worked tirelessly since the very early days of AMNET and provided an invaluable service to everyone in the organisation. On behalf of all members I would like to extend a heartfelt thank you to Ray for his many hours of hard work. However, this isn't goodbye, as Ray assures us he is still willing to provide information to those who need it – if from a little further away. As it will obviously be a little more difficult to organise things at this greater distance we are looking for other members who would be willing to help out with providing information.

Ray can be contacted at:

Tel: 00353 23 56719

email: [ray.maw@btinternet.com](mailto:ray.maw@btinternet.com)

# CAMTAD EXHIBITION

The CAMTAD exhibition was held in the Church of St Andrew the Great, Cambridge from 11th to 16th August. The exhibition was attended by over 700 people over the course of the week, some attendance encouraged by a Town Crier advertising the event on the corner of St Andrew's Street. The exhibition had a wide range of exhibitors from business, public sector and voluntary organisations and there were also talks and demonstrations every day. I was able to collect a large amount of information, some of which I will pass on to you over the next few editions of the newsletter. I also include other impressions from Jill Laurimore and Tony and Eleanor Monk.

## Jill Laurimore

My stint was mid-week and the space was shared with BT. The reactions to the AMNET display re-confirmed how relatively rare Acoustic Neuromas are, something we in AMNET & BANA may sometimes forget. In an exhibition full of people immersed in hearing issues, no one I met had ever heard of them before, and the RNID booklet on hearing loss does not mention them. The most I could therefore do was pass on information, mostly to existing CAMTAD members. There was a mass of other

information available which might well be valuable to our members. The BT team had an impressive display of equipment, not all of it sourced from BT itself - designed to cope with all levels of hearing loss. There is also an organisation specialising in the supply and use of mobile phones for the deaf. The presence of CAMTAD as a conduit for this information is itself a valuable resource for all of us.

## Tony and Eleanor Monk

We attended the CAMTAD exhibition on Thursday 14 August and manned the stall for AMNET between 10.30 and 1.30. The exhibition itself was very interesting and impressive with a wide range of devices to help people with hearing difficulties. We saw 4 people while "on duty", none of whom had heard of AMNET, but were interested because of their symptoms e.g. tinnitus, loss of hearing and the depression caused by these disabilities. BT had a large stall in the alcove off the main entrance where we were situated and this attracted people towards us, but perhaps they would not have come in otherwise. We would have liked some sort of identification badge, but otherwise it was a good thing to have been involved in.

## TIPS & QUERIES

from Jill Laurimore

### Protecting your good ear

Have members any particular tips or strategies for 'guarding' the hearing in the remaining 'good' ear? I try to do obvious things like avoiding heavily amplified music and using an earplug when wielding the noisy old motor mower but that's about it. One AMNET member always has a plug of cotton wool with her and is thus ready prepared when she can see a giant juggernaut bearing down on her. Any other user-friendly ideas out there?

### Tinnitus tip

This had better be for taken as a purely personal piece of information because it goes so against the grain of accepted tinnitus thinking - and it relates only to post-operative tinnitus. The generally accepted advice is for the sufferer to ignore the sounds in their heads or mask them with anything from recorded 'white' noise to background radio, and that is exactly what I did before the operation. I was puzzled by the

existence of post-operative tinnitus though. It was understandable that the sensation could be triggered by the presence of the tumour, but why was it still there afterwards in a totally deaf ear now minus its auditory nerve - albeit it in a much less musical, complex form? It was only when it was explained to me that this post-operative tinnitus was a construct of my brain attempting to react to my deaf ear as if it was normal - in effect a bit like phantom limb syndrome in amputees - that I discovered my own method of removing it. Far from ignoring it, I make myself concentrate hard on the sounds, telling my brain firmly that it is trying too hard, that there's nothing there to hear and it should calm down. The effect is almost instantaneous - a few seconds at the most and the tinnitus fades to nothing. However this only works in quiet situations: in noisy environments it is almost as if there is not enough time of 'peace' for the message to get through, the brain is too busy 'reacting' to the noise. I find it invaluable though, because once again I can enjoy the peace of true silence when I want it. I would be interested to hear if anyone else has experienced this phenomenon.

## Hearing Concern – The charity for hard-of-hearing people

Hearing Concern is a national membership charity dedicated to improving the quality of life for those who are hard of hearing. It is a volunteer led organisation whose main objectives are to provide advice, information and support, to promote communication access and to raise public and professional awareness of the issues associated with hearing loss. It represents 2 million hearing aid users and nearly 9 million people with hearing loss in the UK. They provide:

- A HelpDesk service to all deaf and hard-of-hearing people, their families and friends, whenever they need help or guidance on hearing loss.
- Home visits and one-to-one support through a network of Hearing Advisors
- Access to a network of hard-of-hearing groups around the country.
- Leaflets on topics such as lip reading and hearing aids
- Research into technical solutions to problems encountered by deaf and hard-of-hearing people.
- Campaigns to raise the rights and needs of deaf and hard of hearing people.

Hearing Concern, 7-11 Armstrong Road, London W3 7JL

Help Desk 0845 0744 600 Email: [info@hearingconcern.org.uk](mailto:info@hearingconcern.org.uk) Website: [www.hearingconcern.org.uk](http://www.hearingconcern.org.uk)

# Rachel's Corner

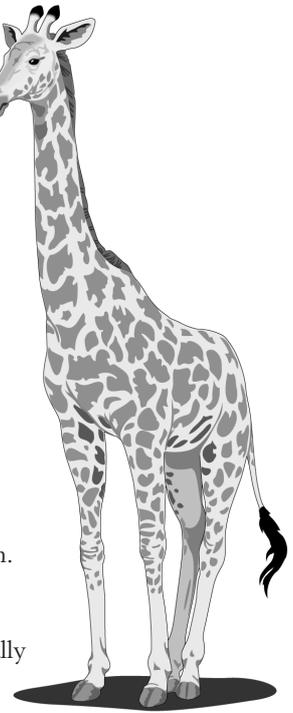
## *The Giraffe Effect*

*This is Rachel Pearson's account of an approach to neck pain which she has found very helpful.*

### THIS MAY COME AS A SHOCK . . . . .

but I am no longer a pain in the neck. Yes, some of you might disagree, but I feel like a new person. And who are you to argue?

As many of you know, some of my head pain actually got worse rather than better, and was eventually diagnosed as severely contracted sterno-cleido-mastoid muscles. Because of my continuing balance problems my body is constantly bracing itself and some of this tension affects the neck. Although initially the surgery side was worse in time the other side came out in sympathy and all pillows spelt misery at night.



Over the years I have sampled many kinds of treatment, some of which helped a little. We in the west are simply spoilt for choice. Thus I have tried over the counter painkillers, prescription painkillers, other prescription drugs, physiotherapy, steroid injections, Botox injections (no, my looks did not improve), cranial osteopathy, wheat bags and massage. I would not knock any of these, but I did learn through bitter experience that very tight muscles do not respond to enthusiastic physiotherapy exercises which encourage you to stretch as far as you can through the pain. The muscles simply take fright and contract further. They need to be stretched, but in minuscule amounts.

The book which has changed my life is not Proust but a little booklet produced by, wait for it, The Stationery Office. I read about it in a line in a newspaper and thought I would take a look at it. It is meant for whiplash patients but has applications for neck problems generally. I tried some of the exercises in the little and often approach recommended and the effect was instant. Within a day the fog in my head had cleared dramatically (presumably due to improved oxygen supply) and the level of pain had begun to subside. One particular side to side exercise has been little short of miraculous in teasing out the tense muscles. The pain reduction has been dramatic.

Do not worry, you do not need to write to Santa or plunder your pension. The booklet costs £2.50. Details are:

#### **The Whiplash Book**

Authors: Professor Gordon Waddell  
Professor Kim Burton  
Tim McClune

Published by The Stationery Office

Available via ordinary bookshops, online [www.tso.co.uk/bookshop](http://www.tso.co.uk/bookshop) and by telephone 0870 600 5522.

Happy reading!  
Rachel

---

## **Deaf-friendly emergency roadside telephones**

(From Sequel- deaf telecoms update produced by Tag (Telecommunications Action Group))

The first Emergency Roadside Telephones (ERT) suitable for use by profoundly deaf and hard of hearing people have been installed on parts of the M11, M25 and A12. By 2005, all ERTs in England should be accessible to deaf people. Features include an LCD display which gives prompts which show call progress and when the operator is on line, an inductive loop and an adjustable volume control for hearing aid users and a high powered ringing tone and flashing beacon in case the operator has to ring back. For profoundly deaf users there is a text system which uses the LCD display and two push buttons to answer 'yes' and 'no' this even operates in a variety of European languages. This new ERT is a major advance in helping deaf and hard-of-hearing motorists to communicate effectively in an emergency.

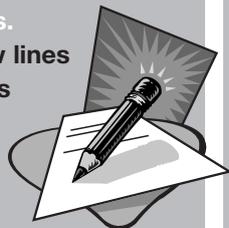
Please think about writing something for your newsletter. It can be anything you feel will be of interest to members.

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](mailto:chris@richards2113.fsnet.co.uk)

by: 12th March 2004



## 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

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.

## FORTHCOMING MEETINGS

Our Christmas meeting will be held on **Saturday December 6th 2003** in The David Dunn Room at Addenbrooke's Hospital and will start at **10.30hrs. Please note the time.** As usual we ask members to bring a contribution towards lunch.

The following meeting, our AGM will be held at Addenbrooke's Hospital on **Saturday 15th May 2004.** The speaker will be Ivy Court, Manager of the Emmeline Centre for Hearing Implants.

**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.

### Also [which-doctor.co.uk](http://www.which-doctor.co.uk)

The new web-site search directory to help you find a doctor with a particular skill, service specialist or research interest, anywhere in the UK.  
<http://www.which-doctor.co.uk>  
email [info@which-doctor.co.uk](mailto:info@which-doctor.co.uk)

### Addresses and Web sites

Addenbrooke's new website  
[www.addenbrooke's.org.uk](http://www.addenbrooke's.org.uk)

Changing Faces  
(Registered Charity 1011222)  
1-2 Junction Mews, London W2 1PN  
Tel 0202 7706 4232

Email: [info@faces.demon.co.uk](mailto:info@faces.demon.co.uk)  
Website <http://www.changingfaces.co.uk>

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

### The Meningioma Association UK

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

Tel: 01787 374084

Email: [MeningiomaUK@aol.com](mailto:MeningiomaUK@aol.com)  
Website: [www.meningiomalUK.org](http://www.meningiomalUK.org)

## 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  
Email [bana@btclick.com](mailto:bana@btclick.com)

## Library

**Book Amnesty** Alison is missing a number of books she has sent out over the years. If you have borrowed books from AMNET we would be grateful if you could check your bookshelves and return any books you may find. This can be done anonymously if you wish. We would just like to keep a good supply for new people who request information.

## 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.

# Surfing the Net?



RNID Tinnitus Helpline  
(Registered Charity 207720)  
Castle Cavendish Works, Norton Street,  
Nottingham NG7 5PN  
Tel/Textphone 0115 942 1520  
For further information:  
Email: [tinnitushelpline@binternet.com](mailto: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](mailto:info@hearingconcern.org.uk)  
Web site: <http://www.hearingconcern.org.uk>

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