

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

Autumn 2008

Issue 44

'Acoustic Neuroma - The Journey to Watch Wait and Rescan'

a talk by Simon Lloyd, Skull Base Fellow, Addenbrooke's Hospital

Reported by Chris Richards



We welcomed Simon Lloyd to our July meeting. He is the Skull Base Fellow at Addenbrooke's Hospital but will soon be taking up a Locum Consultant post in London. He talked about some of the history of identification and treatment of acoustic neuromas and the growing use of the watch, wait and rescan

approach including information on a research study he is undertaking with this group of patients.

History

The first evidence of acoustic neuromas was found by an archaeologist in 1992 in a cemetery in Franzhausen, Austria. They found two children's skulls dating from 2500BC which had widened internal auditory canals. As both sides of the skull were affected and the bodies were those of children it was thought this may be a case of neurofibromatosis type 2 (NF2).

The first postmortem description of an acoustic neuroma was made by Edward Sandefort, a professor of pathology in Leiden, The Netherlands in 1777. He described the tumour he saw in latin as 'a small hard body adherent to the auditory nerve'. He noted that the tumour was also adherent to the brain stem and that surgery would be impossible. This continued to be the opinion until late in the 18th century.

The first clinical description of an acoustic neuroma was made in 1810 by a French doctor Leveque Lasource. In 1830 Charles Bell provided the first description in English. This was a young woman who presented with facial numbness. Charles Bell describes his clinical examination as

'the end of a feather passed three inches into the nostril gives her no sensation and does not produce sneezing'

This illustrated extensive facial numbness. He described her progressing symptoms as facial paralysis, giddiness,

vomiting, indistinct speech, failure of respiration and swallowing, death being caused by compression of the brain stem.

In 1822 Wishart provided the first clinical description of NF2. This was a young man who was found to be progressively deaf in both ears, blind, had intractable vomiting and headaches, and facial twitching. The young man died aged 21 and the post mortem showed numerous tumours in the skull. These were described as

'a tumour of the size of a small nut, and very hard, being attached to each of (seventh and eighth cranial nerves)'

At this time surgery was not possible as there were no effective anaesthetics. Early treatments included

Application of leeches to the mastoid bone
Blood letting from the feet

Electropuncture – passing electric current through the tissues

Application of moxas – a mossy vegetable used in oriental medicine.

By the end of the 19th century doctors had begun to make a correlation between the clinical and the post mortem findings, enabling them to localize tumours on the basis of clinical findings. The symptoms being presented made it possible to identify the auditory canal as the source of the tumours. This began to make surgical removal possible. In the late 19th century there were many unreported and fatal attempts at tumour removal. There is some dissent about whether Charles Ballance or Thomas Annandale was the first surgeon to successfully remove an acoustic neuroma. Ballance carried out a successful operation in London in 1892 although from the description it may have been a meningioma. He was however the first to describe the sub-occipital approach in 1894. The first translabrynthine approach was described by Quix in 1911. Thomas Annandale first successfully removed an acoustic neuroma in Edinburgh in 1895. This was a 25 year old lady who presented with headache, giddiness and right hearing loss which progressed to vomiting. Annandale carried out surgery with an 'eminently successful result'. This was later, in 1917, described by Cushing, another well respected neurosurgeon as *'a brilliant surgical result, the first recorded'*.

Next meeting

The next meeting will be held on **Saturday 29th November 2008** in the Boardroom from midday at **Addenbrooke's Hospital, Cambridge**. We will be joined by Peter Davison who will tell us about his cycle ride from Lands End to John O'Groats to raise money for brain tumour research through Brain Tumour UK. In recognition of his efforts we would like to collect some donations to add to his sponsorship. As usual we ask everyone to bring a small contribution towards a buffet lunch and there will be a raffle.



It was a few years before surgery became more generally successful. Initially only 20% of patients survived surgery but by the 1920s Cushing had modified the techniques by only partially removing the tumour, leaving tumour close to brain stem intact and this led to a much higher survival rate of around 80%. Interestingly as there were very few tests available at this time that would enable surgeons to identify exactly where the tumour was sited it was often necessary to operate on both sides. Over time tests for diagnosis improved and in the 1960's a surgeon called William House pioneered the use of the microscope in surgery which assisted full removal of the tumour and improved survival rates further assisting work towards preserving facial nerve function.

In 1969 Lexell recorded the first use of Gamma Knife as a radiological approach to treating patients with acoustic neuromas related to NF2.

Current Options

The current treatment options for patients with a diagnosis of acoustic neuroma or vestibular schwannoma include surgery with the option of three approaches the translabyrinthine, retrosigmoid and middle fossa, there are also the possibilities of Gamma Knife or Fractionated Stereotactic Radiotherapy. For some patients there is also the option of 'Watch, wait and rescan'.

Watch, wait and rescan

A first paper on the non-operative management of acoustic neuroma patients was published in 1985 by Silverstein who described a study of 211 elderly patient for whom they followed up and measured tumour growth. They found that the tumours were only growing about 2mm per year. The first reference to the term 'watchful waiting' in this context was in 1987. This approach was usually confined to elderly patients, those who were unfit for surgery or had hearing loss on the unaffected side. However these patients offered the opportunity to examine the natural history of acoustic neuromas. This has shown that the number of acoustic neuromas that grow varies greatly from 14 – 75% depending on the series examined. A recent analysis of a number of studies showed that on average 30-40% grow while 8% get smaller. The average growth was shown to be 1.9 mm per year.

With the advent of MRI making it easier to identify small tumours more patients are being offered the option of watch, wait and rescan to monitor the growth of the tumour.

The symptoms that patients present with are:

- 80% hearing loss
- 60% tinnitus
- 25% imbalance
- 2% vertigo
- 7% headache
- 4% facial numbness
- 2% facial weakness

With the exception of hearing loss, there is little information on how symptoms develop over time. Hearing loss does not seem to be related to size of the tumour at presentation, but does progress over time, more quickly if the tumour is growing. Poor hearing at diagnosis usually indicates more rapid deterioration in hearing. This can have relevance as there comes a point at which the patient will not be a candidate for hearing preservation surgery.

The quality of people's lives following surgery has been monitored. Initially survival was the key measurement and then there was more interest in preserving function of hearing and facial nerve. In recent years there has been a greater emphasis at looking at people's quality of life. Studies have shown that this is often lower in post surgical groups than watch, wait and rescan groups and the general population. The results suggest that

- 80-90% patients don't regret undergoing watch wait and rescan
- 20% patients stop work while 10% change their job
- 30% feel there is some impact on daily chores or change in social ability, concentration and fatigue
- Quality of Life is no different from general population

However at present there is not a lot of data as the studies are small.

Watch, wait and rescan at Addenbrooke's

Traditionally the indications for this programme were confined to elderly patients, those who are unfit for surgery or who have lost hearing in the unaffected ear. The indications for entering patients into this programme are changing. It will now include patients with small to medium sized tumours up to around 1.5cm (in Addenbrooke's – it may be slightly different in other hospitals). Most diagnosed patients will now have at least a short period of wait, watch and rescan to see whether the tumour is actually growing as sometimes they do not grow. MRI scans are carried out regularly and growth is defined as 1mm or more a year and may be measured over a number of years to gauge the rate of growth. Treatment will be recommended when the tumour is growing and may be touching the brain stem. Treatment, whether surgery or radiotherapy, is less likely to result in complications in smaller tumours. The patients are scanned yearly for the first 3 years, every other year for 6 years and then every 3 years. To maintain continuity patients are scanned at the same hospital if possible. A database of patients undergoing watch wait and rescan has been kept for 17 years at Addenbrookes with a total of 580 patients of whom 245 are still being observed.

The advantage of this programme is that the patient suffers no complications, However the disadvantages include:

- Loss of candidacy for hearing preservation
- Growing tumour
- Periodic scanning
- Living with a tumour

In the Addenbrooke's clinic 23% of patients in this group eventually have treatment and the commonest reason is growth of the tumour. Of these patients 80% opt for surgery although the proportion having radiotherapy is increasing.

Addenbrooke's Watch, wait and rescan study

The largest study of this group of patients so far is 102 patients with an average follow up of 5 years.

A study is being carried out at Addenbrooke's which aims to include 245 patients. They are planning to review 137 in clinic and have sent questionnaires to a further 60 patients. The average follow up of this group is 4-5 years.

The study will carry out an extensive review of all aspects of these patients in relation to:

- tumour growth
- symptom change
 - Hearing
 - Tinnitus
 - Dizziness
- quality of life
- vocational impact – impact on their ability to work

This will be done through assessment with questionnaires, audiology tests and a clinical examination.

The study is being carried out at Addenbrooke's hospital and will last a year, although follow up questionnaires may be sent in the future. The hope is that a number of academic papers will be published as a result

The team carrying out the study are:

- Primary Investigators
 - Simon Lloyd, Skullbase Fellow
 - Anand Kasbekar, Research Fellow
- Audiologists
- Supervisors
 - David Moffat
 - David Baguley
- Support staff
 - Melanie Jackson, Skullbase Nurse Practitioner
 - Bianca Saunders, Secretary to Mr. Moffat

We would like to thank Mr Lloyd for giving up his time and providing an interesting and informative talk and we wish him success with his study. AMNET have made a small donation towards this research. Any patients who feel they may qualify for the study but have not received an invitation may like to contact Clinic 10 at Addenbrooke's Hospital.



postbag

Stephen West has sent us a couple of updates following his radiotherapy treatment in May/June 2006.

June 2008

Since having Radiotherapy treatment at Addenbrookes for my acoustic neuroma during May/June 2006, I am continuing to progress with few side effects apart from the ongoing Tinnitus for which I have been prescribed a hearing aid and this is helping to reduce the sound of the Tinnitus whilst also making me aware of sounds which I was unable to distinguish without the hearing aid.

I have found that I get tired quicker and have less energy than I did have prior to 2006 but this may not be directly related to the treatment because I have two teenage children at home and balancing full time shift working with a busy home life can be quite tiring in itself.

October 2008

I have just had a meeting with the consultant at Addenbrookes to analyse the results of my two year post FSR radiotherapy treatment.

I was very pleased and encouraged to be told that the results of my MRI scan indicated further shrinkage of the tumour cells, all indications showed that the radiotherapy has been successful.

I asked if I could see the change and was shown two images from my MRI scans, comparing the two MRI scans taken at one year then two year and they do seem to indicate that the acoustic neuroma is getting smaller and less defined.

Both my wife and I were greatly encouraged by seeing this.

My next MRI scan will now be two years from now (ie at year 4 from the treatment) I have also got an appointment for another review with the consultant in 12 months time. This offers me further encouragement, because the last thing I want is to feel abandoned after treatment.

Best wishes

Stephen West

Our thanks to Gary Birnie's cousin for the donation to AMNET.

Editorial

Dear all

Welcome again to our newsletter and let me be the first to wish you a Happy Christmas and Best wishes for the New Year.

This edition of the newsletter includes a report of the talk given by Simon Lloyd about the 'watch and wait' programme at Addenbooke's Hospital and describes the research they are doing to find out more about this group of patients.

Many of you will remember Peter Lawrence's article in the newsletter last year in which he described his search for the best treatment for his acoustic neuroma. As his tumour was growing he made the decision earlier this year to have Gamma Knife treatment and has written an account of his

treatment and provided us with pictures. He also contests some of the comments made by Mr Moffat when he spoke to us last year which I am hoping may start an interesting debate. If you have any thoughts you would like to add to the discussion please write to me and I will publish them in the next newsletter.

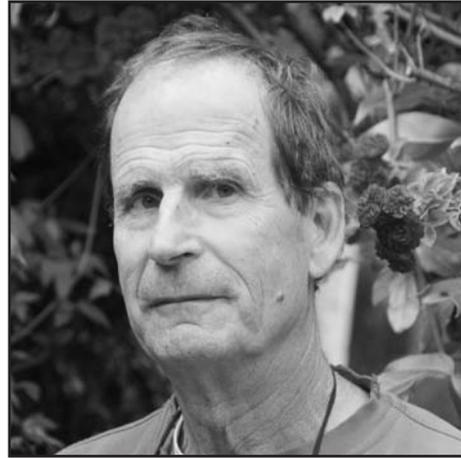
We look forward to seeing as many people as possible at our Christmas meeting when Peter Davison will be coming along to tell us about his bike ride from Land's End to John O'Groats in order to raise money for brain tumour research and we also hope to be welcoming Melanie Jackson, Specialist Nurse from Clinic 10. Of course there will also be our usual buffet lunch and raffle. So until then....

Regards

Chris.

Most of you will remember Peter Lawrence's article in an earlier newsletter about his search for information after being diagnosed with an acoustic neuroma. He has now provided me with the sequel. He also raises some arguments against points made by Mr Moffat in his talk to us last Christmas.

Peter Lawrence and his acoustic neuroma



It was about 18 months ago when I wrote in Amnet news. I had a "moderate" acoustic neuroma and I had decided to go for stereotactic radiosurgery (GKRS), and I had chosen the unit in Sheffield, the only NHS unit in the country and specifically Mr J Rowe, as I liked the cautious and objective way he weighed up the evidence both when he talked to me and when he wrote his papers.



The team waiting for the patient.

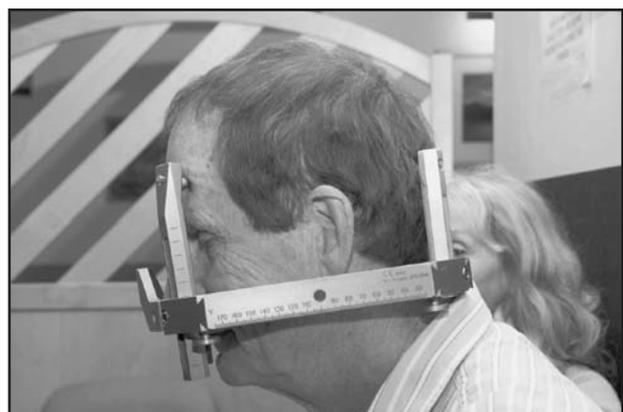
The advice of both Mr Rowe and Mr Moffat in 2006 was not to undergo GKRS unless the tumour was found to be growing. But by spring it was clear that the alien had been growing, slowly. When first found it was about 0.9 cubic centimeters, but 18 months later it had reached about 1.3 cubic centimeters. Mr Rowe advised me to go ahead with the GKRS as the smaller the tumour the more effective the treatment.

I had this treatment in June 2008 and I took some pictures and handed my camera around to provide a record.

They gave me a gentle sedative pill that helped I am sure. Then the frame is attached, this was done out of my sight, and so you sit in a chair and all you feel is stinging from the local anaesthetic and before you know it you have a frame screwed into the skull in 4 places. Mr Rowe said it would feel like a hat, and I didn't really believe him, but once I was off the chair, my skull was numb and the truth is it felt like the radiohat I listen to cricket with when gardening.

Then into an MRI machine to get a 3D picture that precisely places the tumour vis a vis the frame. A few minutes in there followed by a period of waiting while the physicists use fancy software to work out a "treatment plan". The aim is to irradiate the tumour with a hefty dose that will seriously damage it while sparing the brain, not even the important nerves that adhere to the tumour (thankfully they are never buried in the tumour). The principle is to send 201 pencil-thin beams of irradiation with sharp edges that come in from different directions and only meet on the tumour itself. The tumour is irradiated piece by piece until it is all done. And the sources of the pencil-thin beams are varied by moving, under computer control, the head slightly vis a vis the beams, so that any piece of brain is only hit by one of these beams. The diameter of the beams can be varied, by varying hole sizes in the collimator (This is the metal hemisphere you see in the picture to which me and my frame is locked). Cells are supposed to tolerate about 1.8 grey pretty well, and the dose at the tumour edge is fixed at 12 grey, so it should have been properly cooked.

Anyway, I lay on the machine and two radiologists, who were brilliant, fixed my frame to the collimator, left the room and I was moved into the machine, the collimator docked with the source of gamma rays for about 4 minutes, then there was a pause and my head was moved almost imperceptibly to a new position and another part of the



Fitted with the head frame.



Gamma Knife machine.

tumour was targetted. This was repeated 5 times. Then out again, changing the collimator to a smaller one, to hit two outlying bits with smaller beams, and that was that. The frame was then removed and it was all done.

I was told to rest up a little, not wash my hair for three days so that the holes on my scalp could heal. We went out for supper at a restaurant immediately afterwards and I drove home to Cambridge the next day and was back in the garden with my radiohat on by lunchtime. I thought that if there were to be any nerve damage I would detect it immediately, but not so, any nerve damage will not show

for 6-9 months. Mr Rowe thinks my hearing may deteriorate (and this is expected, with or without the treatment) but there will be no damage to my facial nerve.

If GKRS works as well as neurosurgery for acoustic neuromas, and the modern literature argues that it does, with similar relapse rates of some 3-5% then there is no contest. I am back at work the day after and I have good hearing on both sides. GKRS is a doddle compared to a big skullbase operation.

It is now September and I feel just as I was before the radiosurgery and hear just as well. Obviously I don't know what the future will bring, but there are plenty of grounds to be optimistic.



Going into the Gamma Knife machine.

Mr Moffat raised some arguments against GKRS in his talk to AMNET last year Peter puts these points in response:

1. ***"the reported results may be spurious"***.

1. This is true, but it applies equally well to the results of neurosurgery which are just as difficult to collect objectively and to make comparative assessments over long periods. The best comparison is the Mayo Clinic study which concluded that "GKRS should be considered the best management strategy for the majority of AN patients"

2. ***"The tumour swells following GKRS"***.

1. There is some swelling with some tumours but is not a problem in practice. Mr Rowe had had only one case from about 1300 where the GKRS had failed and a swollen tumour had to be removed by surgery.

3. ***"Hydrocephalus has been reported in 2-6% of patients following GKRS"***.

1. What this means is not so clear. In a Sheffield series of 234 consecutive patients, 3 patients required a shunt an average of 16 months after radiosurgery; however it cannot be concluded that the need was caused by the radiosurgery as 9 patients had required shunting before the radiosurgery (because of their acoustic neuroma). How to interpret these and other data? There is a strong correlation between tumour size and the likelihood of requiring a shunt either with or without radiosurgery; the larger

tumours being more likely to give rise to hydrocephalus. Complicating the issue is a change in practice, nowadays smaller tumours are detected and treated with GKRS. Nevertheless, when treating patients with larger tumours, patients and clinicians should be aware that hydrocephalus may be a risk.

4. ***"Malignancy might be induced by irradiation"***.

1. This was a worry but there was never any convincing evidence and now an objective study of 30,000 patient years has shown that the frequency of malignant tumours is not different from a control untreated group.

5. ***"Facial nerve preservation is poorer when surgery follows failed GKRS"***.

1. This argument can be turned equally well on its head, as treatment by GKRS following failed surgery is also problematic. The key information is the frequencies of failures of different kinds from both approaches, the trauma and the risks associated with both kinds of interventions and the quality of life for patients thereafter and for that I refer readers again to the Mayo Clinic paper which comes down unequivocally for GKRS for small tumours. Even in that paper it would be nice if both groups of patients had been followed up longer, so questions will remain for some more years. But clinicians are becoming more scientific in the way they gather and assess results and (at last) all would probably now agree that this is the only way forward.

Minutes of AMNET AGM Saturday 5th July 2008 held at Addenbrookes Hospital

Minutes of last AGM held on 7th July 2007
were accepted as a true record

Chairman's Report

AMNET is 12 years old and thriving! We have been lucky to gain a lot of extra help and helpers this year. In the Autumn of 2007 Janice Pettit joined our committee and despite having had her operation in January 2008 and having some problems was able to attend meetings in April. Caroline Shepherd has taken over distribution of the newsletter from Thelma and Bill Pye and this is running smoothly. Joanne has Rachel Pearson to help her with membership renewals and subscriptions so these are kept efficiently up to date. Anne Whitlam is our new watchdog for Clinic 10 making sure AMNET newsletters, leaflets and posters are up to date and visible.

Neil and Jill come to committee meetings when they can and are in touch as appropriate. With the new leaflets and joining form in the newsletter we do not need a New Patients Officer so Neil's original job will not be replaced. Jill has lots of other commitments so we are glad she was able to be secretary for a year. John Peartree has taken this on so Chris and I have some extra back up. Chris, Jo, Margaret, Ella and I plod on as before! Although not on the

committee Eleanor and Tony have continued to serve refreshments for us.

On the medical side we have strengthened our links with staff from Clinic 10, having had various meetings with Simon Lloyd, David Baguley, Rachel Knappett (new audiologist) and Melanie Jackson (specialist nurse). The latter has been particularly helpful, my having contacted her about numerous patient queries and her being available for first hand AMNET members. I am pleased to say she has agreed to join AMNET's advisory board and hopefully will be at our Christmas meeting.

Our meetings have been successful this year. We welcomed Mr Moffat back in November and were able to celebrate his operating on the 1000th A.N. patient, Peter Moss at Addenbrookes. AMNET members thought this was a marvellous achievement and the packed meeting was brought right up to date. Mr Moffat has gleaned much information and contributed useful statistical data since he started here in 1981.

In April Sarah Jefferies, Clinical Oncologist came to talk to us about radio therapy treatment for

Acoustic Neuroma which should now be called vestibular schwannoma. This talk extended our knowledge, particularly for those of us who were 'only' involved in surgery. We are now having 3 meetings a year. Any comments on this either for or against would be welcomed. Our website with its new email is getting well used by over whelmed prospective patients, medical staff, browsers and single question enquirers. We are grateful to Paul at Greystoke Graphics for regularly updating the website free of charge.

There is still lots of room for more people to help expand and improve AMNET. If you would like to help please contact myself or one of the committee. This can be a one – off, short or long term commitment. One specific job is helping with the refreshments at the Christmas meeting on November 29th 2008 as Eleanor and Tony are unable to be there.

My thanks as before to all who have helped AMNET in large or small ways so we can continue to help those who need us.

Treasurer's Report

The books have been audited for last year by Michael Bartlett.

The balance at the end of the financial year was £2673.73. There was a deficit of £1111.49 which was due to the fact that we purchased three new trophic stimulators, made some donations towards research into acoustic neuroma and also had leaflets printed which are being distributed in the hospitals within the region. However revenue from subscriptions was a little higher than last year reflecting a slight increase in new members joining.

Election of Officers

Office	Officer	Proposed	Seconded
Chairman	Alison Frank	Chris Richards	Jim Metham
Treasurer	Joanne See	Rachel Pearson	Bronwyn Lummis
Secretary	John Peartree	Jill Laurimore	Joanne See

Other Committee members:

Neil Bray
Chris Richards
Margaret Allcock
Ella Pybus
Janice Pettitt

Neil Bray will no longer be New Patient's Officer and Jill Laurimore will be withdrawing from the committee as she will be moving but will continue attend when possible.

Publicity and promotion

Chris Richards – Newsletter Editor emphasised the importance of contributions to the newsletter from members as people like to read about other people's experiences She also highlighted that the newsletter was being recognised elsewhere and there had been requests to reproduce articles from BANA and Hearing Concern.

Any other business

Provision of microphone for meetings. – the committee are investigating this and hope to be able to provide a radio microphone for speakers.

Margaret Allcock made us aware of a smoke alarm with a handset people can keep with them if they are concerned that they may not hear an alarm when they are sleeping.
<http://www.fireangel.co.uk/>

Trophic Stimulators

Margaret Allcock who manages the trophic stimulator will be away for an extended holiday early in 2009. Janice Pettitt has agreed to look after the trophic stimulator hire while Margaret is away and will take over at Christmas.

**Janice's telephone number is 01763 243998 and
email is dandjpettitt@haygate.wanadoo.co.uk**

FORTHCOMING MEETINGS

The next meeting will be held on **Saturday 29th November 2008** in the Boardroom from midday at **Addenbrookes Hospital, Cambridge**. We will be joined by Peter Davison who will tell us about his cycle ride from Lands End to John O'Groats to raise money for Brain Tumour UK. In recognition of his efforts we would like to collect some donations to add to his sponsorship. As usual we ask everyone to bring a small contribution towards a buffet lunch and there will be a raffle.

Dates for 2009 are not confirmed as yet but they are provisionally booked for March 28th /April 4th, July 11th (when we hope to have Diana Farragher speaking) and November 28th. (David Baguley as speaker.)

The BANA AGM will be held on June 27th 2009 in Nottingham.

AMNET Advisory Panel at Addenbrooke's Hospital, Cambridge

Mr David Baguley MSc MBA
Principal Audiological Scientist

Kate Burton
Consultant Radiographer in Neuro - Oncology

Jean Hatchell
Clinical Nurse Practitioner

Melanie Jackson
Skull Base Nurse Practitioner

Mr Robert Macfarlane MD FRCS
Consultant Neurosurgeon

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

Ella Pybus
Co director Meningioma UK & Trustee of
BTUK

Mr N J C Sarkies MRCP FRCS
FRCOphth Consultant Ophthalmic Surgeon

BANA Booklets

BANA has produced some 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**

**Effects an acoustic neuroma can
have on your memory,
emotions, behaviour, executive
functioning and energy**

All these booklets are available from Alison. There is a charge of £2.00 for all except for the first title.

Contributions

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:
chris@richards2113.fsnet.co.uk

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

Facial Stimulators

AMNET has some Facial Trophic Stimulators which are available to members for short term loan. There is a charge of £30 at present which includes maintenance and postage. If you would like to know more please contact: **Margaret Allcock on 01493 700256.**

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	Treasurer	Newsletter Editor	New Patients Officer
Alison Frank	Joanne See	Christine Richards	Neil Bray
01953 860692	01487 814380	01954 211300	01223 561234

Directory

AMNET

Web site address:

<http://amnet-charity.org.uk/index.html>

Email: contact.amnet@btinternet.com

Telephone: 01953 860692

Address: The Old School House, The Green Old Buckenham, Norfolk NR17 1RR

British Acoustic Neuroma Association (BANA):

Web site: <http://www.bana-uk.com>

Email: admin@bana-uk.com

Telephone: 01623 632143 **Fax:** 01623 635313

Freephone: 0800 652 3143

Address: Oak House B, Ransomwood Park, Southwell Road West, Mansfield, Notts NG21 0HJ

Meningioma UK:

Web site: <http://www.meningiomauk.org>

Email: support-enquiries@meningiomauk.org

(patient information & support)

meningiomauk@ellapybus.greenbee.net

(Meningioma UK)

Telephone: 01787 374084

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

Brain Tumour UK:

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

Telephone Helpline: 0845 4500 386 (10am - 1pm, Monday to Friday).

Address: PO Box 27108, EDINBURGH, EH10 7WS

Royal National Institute for the Deaf (RNID):

Web Site: <http://www.rnid.org.uk>

Email: informationline@rnid.org.uk

Information Line (Freephone)

Telephone: 0808 808 0123

Textphone: 0808 808 9000

Tinnitus Helpline

Telephone: 0808 808 6666 (Freephone)

Textphone: 0808 808 0007 (Freephone)

Address: 19-23 Featherstone Street, London EC1Y 8SL

Cambridge Campaign for Tackling Acquired Deafness (CAMTAD):

Web site: <http://www.copag.members.beeb.net/copmoc/camtad.htm>

Telephone/Textphone/Fax: 01223 416141 (Mon - Fri 09.30 - 12.30)

Address: 8A Romsey Terrace, Cambridge CB1 3NH

Also contact point for Cambridge Hard of Hearing Club and Cambridgeshire Tinnitus Support Group

Changing Faces:

Charity offering support for people with temporary or long-term facial disfigurement problems

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

Email: info@changingfaces.org.uk

Telephone: 0845 4500 275

British Tinnitus Association:

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

Email: info@tinnitus.org.uk

Telephone: 0800 018 0527

Minicom: 0114 258 5694

Address: Ground Floor, Unit 5, Acorn Business Park, Woodseats Close, Sheffield, S8 0TB

Entific Medical Systems:

Information about bone conducted hearing aids, particularly for single sided deafness.

Web site: <http://www.entific.com>

Addenbrookes Hospital: Neurotology and Skull Base Surgery Unit

Web page:

http://www.addenbrookes.org.uk/serv/clin/surg/neurotol_skullbase1.html