Newsletter of The Acoustic Neuroma and Meningioma Network

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 2007
Issue 39

'Handicap in Acoustic Neuroma'

A talk by Rachel Humphriss, Clinical Scientist (Audiology) Addenbrookes Hospital, Cambridge

Reported by Chris Richards

For our Christmas meeting we welcomed Rachel Humphriss who came to talk to us about balance problems in acoustic neuroma and some new developments in testing balance problems. She had presented some of this information to the British Academy of Audiology Conference earlier in the week.

Rachel began her talk with a revision of the anatomy of the ear using diagrams and MRI scan pictures to show how an acoustic neuroma grows with the impact on surrounding tissues as the size of the tumour increases from being just within the auditory canal (intracanalicular) to extending into the cerebellopontine angle to the stage where it may actually be pressing on the brainstem.

Vestibular Issues in Acoustic Neuroma

Dizziness occurs in between 49 – 66% of acoustic neuroma patients, although it is the presenting symptom in only 10-14% of cases. In many patients there has been central compensation. This occurs when the tumour is slow growing with loss of balance function from the ear also occurring slowly. In these cases, especially if the tumour is small, the brain is able to adjust and compensate for loss of balance and the patient does not suffer dizziness.

A study carried out on pre-operative acoustic neuroma patients at Addenbrooke's using a questionnaire called the Dizziness Handicap Inventory (DHI) showed that in 145 patients the level of handicap from dizziness was spread fairly evenly from none through mild and moderate to severe (Humphriss et al, 2006).

Handicap level	No Patients (%)
None	36 (25%)
Mild	40 (28%)
Moderate	34 (23%)
Severe	35 (24%)

The study concluded that 75% of preoperative acoustic neuroma patients had some degree of dizziness.

A further study looked at change in the Dizziness Handicap Inventory (DHI) from pre-operation to three and twelve months post operation (Humphriss et al, 2003). They studied 100 patients and found that the DHI scores worsen significantly over the first three pre-operative months but they do not change significantly between three and 12 months. Those with smaller tumours are more likely to

Next Meeting

Next meeting will be held on **Saturday 14th April 2007** in the **Boardroom** at **Addenbrookes Hospital.** The speaker will be **Rachel Rowlingson, Occupational Therapist who will speak about 'Coping with fatigue'. Doors open at 13.00 All welcome.**

AMNET is a member Organisation of BANA, The British Acoustic Neuroma Association
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have no change in scores pre and post operatively and results in the caloric test to measure the degree of loss of balance show that patients who have lost a larger amount of balance are more likely to have a better outcome after surgery. This information can be helpful in counselling patients before surgery.

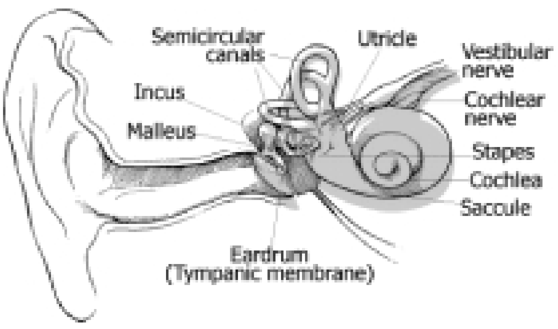
Studies have been carried out looking at quality of life in acoustic neuroma patients. A recent study (Myrseth et al 2006) of 199 patients using well recognised questionnaires suggested that vertigo is the symptom which causes the most pronounced negative effect on scores for quality of life with unilateral hearing loss and tinnitus having less effect.

Another study (Martin et al 2001) of 76 patients suggested that postoperatively 74% of patients had some dizziness which was provoked by movement and 28% had incapacitating balance problems. The study also showed severe balance problems being associated with reduced social functioning.

Vestibular rehabilitation consists of exercises which challenge balance and these have been proved to be effective in post operative acoustic neuroma patients. In a move to do something about the degree of dizziness handicap being suffered by pre-operative acoustic neuroma patients vestibular rehabilitation exercises are now being introduced to patients to do before surgery. Vestibular rehabilitation is also being introduced for non surgical patients such as the 'watch and wait' patients and those receiving stereotactic radiosurgery who may also suffer dizziness some for the first time after treatment.

Vestibular evoked myogenic potential (VEMPS)

Rachel then went on to describe a new technique which is being developed to assist diagnosis and identifying which nerve of balance is being affected by the acoustic neuroma.. Myogenic means muscular and the test is based on the vestibule-collic reflex which is activation of the neck muscles by an acoustic sound stimulus. Balance is maintained through stabilisation of the reflexes from the ear and the eye but also involves the neck muscles which keep the head stable.



The saccule is one of the sensory organs of the inner ear and is primarily related to balance but it also has some sensitivity to sound and this forms the basis of the VEMP test

The purpose of this test is to determine if the saccule, as well the inferior vestibular nerve and central connections, are intact and working normally. The inferior vestibular nerve also serves the posterior semi-circular canal while the superior vestibular nerve serves the horizontal and anterior semi-circular canals.

The test is carried out by placing electrodes on the sternocleidomastoid muscle in the neck, on the sternum and on the forehead. These electrodes can monitor the activity of muscles. A series of loud clicks are made into the ear. Sound stimulates the saccule, traverses the vestibular nerve and ganglion to reach the vestibular nucleus in the brainstem. From there, impulses are sent to the neck muscles causing these muscles to contract which will produce a reading from the electrodes. If in an acoustic neuroma patient there is a normal caloric test indicating there is no balance loss but the VEMP response is absent it will indicate that the tumour is affecting the inferior vestibular nerve. This can be helpful to the surgeons when they are planning the operation. This technique is still in it's infancy but it is hoped that it will prove useful in the future to surgeons when planning operations.

Rachel learned about these techniques when she attended the Advanced Balance Course held at Southampton University in June this year. AMNET provided some sponsorship towards her attendance on this course.

We would like to thank Rachel for an interesting and informative talk which was given

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This picture, taken at the Christmas meeting, shows some of the members who support our work. From Left to right Margaret Allcock (Trophic stimulators), Thelma and Bill Pye (Newsletter distribution), Neil Bray (Committee member), Chris Richards (Newsletter Editor), Jo See (Treasurer), Jill Laurimore (Secretary), with well earned 'Thank you' gifts.

postbag

Thanks to Anne Whitelam for this helpful tip.

Dear Editor,

I just wondered if these few words would be of interest to any acoustic neuroma patients or members. Just before Christmas I went to the doctor with pains in the ear and throat, thinking that I had an ear infection or the like! It turned out that I had shingles on the right side of my head the site of my operation, apparently it affected the trigeminal nerve, I guess it was the weakest point. I have to say the doctor acted quickly and gave me antiviral tablets and I am quite sure that helped me get over the pain much more quickly. The pain was unbelievable and at times I had to resort to a frozen ice pack to give me temporary relief. A month later I am now left with a very red and itchy right forehead and have tried many pills and potions including the doctors' last resort of cortisone cream which aggravated it even more. A friend suggested I used witch hazel cream and this seems to calm it for a while and I can reapply it as and when I need. I hope none of you get this problem, but if you do you may remember the witch hazel! I hope you all have a very happy and healthy New Year. I look forward to seeing you all at the next meeting in April,

Sincerely Anne Whitelam

Editorial

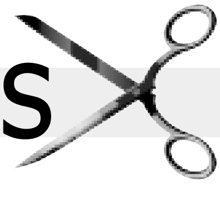
Hello Everyone

Welcome to the first edition of AMNET News for 2007. I hope you find it interesting we have the report on Rachel Humphriss' talk on balance from the Christmas meeting, an update from Steve West and an article from Peter Lawrence which outlines his experience in making a decision about treatment of his acoustic neuroma which also included information he gained along the way.

Last year was an eventful year for AMNET in which we hosted BANA's AGM and also held our own 10 year anniversary celebration. For this year we plan to be looking forward to how we can respond to the changes which are taking place in the management and treatment of acoustic neuromas and meningiomas by working with clinicians and other hospital staff in the way which best helps and supports our members and those newly diagnosed with these tumours. I hope those of you who have been with us for a long time as well as new members will support us as we work towards defining our role in a changing environment. Any ideas and suggestions about how we can move forward will be gratefully received.

Chris.

Snippets



BANA AGM

The BANA AGM this year will be held on Saturday 23rd June at Bushey Baptist Church, Chalk Hill, Oxhey, Watford WD19 4BX, and as this is within fairly easy travelling distance we thought some members might be interested in attending and we could possibly organise transport. The speakers will be Mr Addie Grobbelaar who will speak about RAFT – Restoration of Appearance and Function Trust, and Professor Wright who will speak about subtotal removal of Acoustic Neuroma. If you are interested in attending please speak to Alison.

Trophic Stimulators

We are in the process of replacing our Trophic stimulators which can be hired from AMNET through Margaret Allcock on 01493 700256. These have to be used with the help of a physiotherapist and with work can substantially improve facial palsy and synkinesis. We are grateful to The Lindens Clinic (Diana Farragher) for allowing us a substantial discount on the machines which has helped AMNET's finances.

Hearing Badges

These Badges are available from the American Acoustic Neuroma Association. If you would like one please speak to Alison.

This article was sent in by Andy Johnson is an account of a charity walk undertaken in Snowdonia nine months after surgery to remove an acoustic neuroma nine months earlier. Thanks for the pictures as well Andy – they are inspiring!

Cadair Idris

At 8am on the morning of 16th September 2006, date of the last AMNET meeting, I was tucking into a hearty Full English breakfast provided by our jolly landlady who, for those readers who watch too much TV, sounded just like “Mrs Overall” the Julie Walters character in “Acorn Antiques”. Together with 8 work colleagues, and 2 dogs, we’d pretty much taken over the Barmouth B&B for the weekend in order to take part in the charity ‘Water Aid’s, fund raising Corbett challenge. This involves getting a team on to the peak of every mountain over 2500feet high in the UK between noon and 2pm on the same day.

By 9am we were into our walking gear and setting off at the base of Cadair idris in SW Snowdonia. Normally I’d have considered this a fun day out but this time I started out with a degree of trepidation. My acoustic neuroma was removed between Christmas and New Year and this was the first time I’d attempted anything strenuous in the 9 months since.

The first difference I noticed was simply the difficulty in keeping up with my colleagues. We trod a fairly steep but well marked path up to the point where a splendid tarn comes into view, by which time I realised just how unfit I’d become during 3 months of doing nothing post op, followed by another 5 or 6 months of still not doing a great deal! I also have to confess here that having arrived the previous evening we did venture into a local hostelry, in search of food, but didn’t leave ‘til midnight, so I may not have been at my best for reasons you can imagine.

I plodded on, towards the rear of the group, and we reached the summit at about half past one, where we all stopped to take lunch. We weren’t alone; a bright sunny day had brought out lots of walkers including another two teams doing the Corbett challenge. I’d been concerned about my balance, but, although I concentrated a little more than usual on my footing, I had little trouble even on the rocks and scree sections just below the summit. By September I had some recovery of the facial nerve function and was able to smile, after a fashion, but eyebrow, side of the nose and corner of my mouth were still unresponsive. I’d noticed that even during the hayfever season my nostril on the affected side remained dry. Today however, as I worked hard I regularly had to use my handkerchief, even though my “normal” nostril was fine. I found this quite disconcerting and although I still experience this phenomenon for instance when I now go swimming I’ve been reassured that it’s nothing to be concerned about. I wonder how many of us, having undergone this sort of surgery, get a little anxious when these odd symptoms arise. I guess that’s one of the great benefits of joining AMNET, being able to discuss things with others in the same situation.

Anyway having reached the peak of Cadair Idris, and enjoyed the spectacular views, our group split into two teams and headed off to our allotted sub-peaks which we reached before the 2pm deadline. The descent was tough on the knees but otherwise fine.

We once again visited a local pub that evening but there was lots of background noise and finding it difficult to follow the conversation I retired before the rest, at about 10.30.

Next morning I learned that a couple of our younger members had visited the “Best night club in Wales”, £5/head entry, along the sea front in Barmouth and were now feeling the worse for it. Serves them right I say!

It was a long drive home but we’d had a fun weekend and raised about £1500 between us for Water Aid. My concerns about impaired balance had proved unwarranted and I’m sure the more exercise I do the better it gets, not to mention the benefits of shedding those extra pounds I’d put on earlier in the year.

The group who climbed Cadair Idris. Andy is second from the left on the back row

As you will remember Steve West has been keeping us updated with his progress after having Fractionated stereotactic radiotherapy (FSR) as treatment for an acoustic neuroma. He has experienced some setbacks since his last letter which are recounted below.

From Steve West

I thought that other AMNET members may be interested in the latest developments regarding my experiences post FSR treatment for acoustic neuroma in May/June 2006.

Since writing that article for the winter 2006 newsletter, I have unfortunately had to take some time off work due to having some problems which caused me to experience double vision when looking down. I also noticed that my balance was not as good as it should be and I was also getting very tired.

All of these difficulties seemed to come on very suddenly whilst at work during October 2006.

As those of you who read my previous articles will know; my experience of undergoing the Radiotherapy treatment had been very good up to this point.

I contacted the Oncology department at Addenbrookes as soon as I realised that something was not right and I was seen by Mr Burnet the next day and had an MRI scan the following week. Unfortunately there appears to be no direct link between the symptoms I have reported and my having Radiotherapy treatment, so each problem is being treated individually.

On a positive note I was told that the acoustic neuroma has shrunk by 1mm and is showing all indications of the FSR treatment being successful, which is very good news.

I am writing this note in January 2007. Having been seen by both Ophthalmology and Oncology consultants at Addenbrookes, I am pleased to report that the problem with the double vision seems to be improving now. This problem has so far been attributed to a palsy of the 4th Cranial nerve and was probably caused by working under a lot of pressure whilst getting tired due to having to catch up with developments at work, which had occurred during my absence for radiotherapy. My energy levels and balance also seem to be improving but I am not yet back to 100% fitness. Walking in narrow or crowded spaces particularly after dark still gives me difficulties but does seem to be improving slowly.

I have to return for see both consultants for follow up appointments and a further MRI Scan later this month.

Finally, with regard to all the staff at Addenbrookes who I have dealt with since reporting these problems, as before, I can not praise the staff highly enough. I have been seen quickly, everyone has been very helpful and patient.

Although the combination of problems I am experiencing appear to be unique, everyone appears to be doing all they can to get me back to feeling as well as I did when I finished my Radiotherapy treatment in July 2006.

The most recent update from Steve was in February and is included below.

So far there has been no reoccurrence of the symptoms that caused me the problems last October. Basically the rest has done me some good and the problem with my vision (attributed to a burst blood vessel causing a palsy of the 4th cranial nerve) has got better on its own. The consultants and staff at Addenbrookes have all been very supportive and helpful but at the moment they are not linking the eye problems directly to the Radiotherapy. It is quite probable that after returning to work I got tired and pushed myself too much.

The lesions of the cerebellum, which were identified on a scan I had when I first noticed the eyesight problem, have got smaller and are grouped around where the radiotherapy was given, but what has caused them is still not clear and I am hoping that when my next scan is done at 1 year post treatment (July) they have gone.

I do get tired quickly and when tired my balance is not as good as it was but I can still cycle and keep up with family life.

I started work again last week. My boss has been very understanding and agreed that it is best for me to limit the number of days I work each week, starting with 2 days and gradually increasing over the next month or so, until I am used to the effort needed to take up my place in the 24/7 shift work roster that I have been used to in the past.

I would like to thank Peter Lawrence for this interesting article which I hope will be helpful to others who find themselves in the position of having to make a decision about treatment choice.

Acoustic neuroma/Vestibular schwannoma. A patient's viewpoint on choices and doctors.

by Peter Lawrence

Provisos: I am a biologist not a medical doctor. I have become a bit of an expert on these things, but it is only an armchair expert, through reading and talking to medics. I have no medical experience and my views should therefore be regarded as suspect — my decision process may be different from that of others. Also note that I paid for these consultations myself, you might not get so many on the NHS.

Diagnosis

I had some tinnitus for years but had taken no notice, however my trouble really began at Wimbledon in June 2006 when jumping down from a bench, I got my first ever attack of vertigo, the world rotated for a second or so and it was scary. The same day I had some dizziness, so I went to the GP who thought it was a virus and sent me home. But the dizziness came back with a bit of nausea and the GP sent me off to the neurosurgeon, who I asked to see purely because I had seen him years before. I think this was lucky because I don't think most ENT doctors would have sent me for an MRI scan, my hearing was normal and symmetrical and balance tests showed nothing.

Anyway the MRI scan showed a acoustic neuroma of "moderate" size, 1.65 x 1 x 0.8 cm, sitting in the usual space in the cerebello-pontine angle and just touching the cerebellum. As is typical it extended a little into the ear canal. I started to read scientific papers and over the course of the next 3 months saw 4 consultants and changed my plan after each one!

As a scientist I came to realise how poor the data on treatment is. There are no truly objective comparisons between treatments, follow up periods are usually inadequate and groups of patients are not matched. No ideal trials have ever been done, nor probably ever will — they would involve getting a large set of patients and randomly assigning them to the different methods of treatment and no treatment, and then following them all up for at least 10-20 years.

Consultant 1 The Neurosurgeon

The neurosurgeon discussed my treatment, he seemed to be advising microsurgery but warned us of the possible problems: the certain loss of hearing from the usual approach, translabyrinthine which destroys the ear; or if the retrosigmoid approach is used this can spare the ear, but they can't see so easily into the canal, so can't be sure of removing the whole tumour and there is a chance of damaging the cerebellum (it has to be retracted to get at the tumour); or the middle fossa approach, for which my tumour was already too big, which can cause epilepsy. In all cases there is a risk of some 0.5-1% of the operation being lethal, there is a fair chance of having problems with leaking of cerebrospinal fluid,there is about a 3 month recovery period and they take material from your leg to seal the brain cavity. The neurosurgeon was doing his duty in telling us of all this, but it was daunting. I got the impression I would have to have the operation and I told my friends that this is what I expected. However the neurosurgeon said he would put me on their list but that I should see the oncologist, who specialised in stereotactic fractionated radiotherapy (SRT).

Consultant 2 The Oncologist

The oncologist was very helpful and understanding and discussed with me two forms of radiation treatment, SRT and gamma knife radiosurgery (GKRS). Scientific papers suggested that both work as well as operations, with less risk, and little danger and in the case of GKSR with only a day off work. But SRT is very recent and GKRS has only been around with the present dose regime for about 15 years. GKRS involves a single large dose of radiation from a huge machine built by Elekta in Sweden, there seem to be only 3 in England, 2 in London, 1 in Sheffield. It has about 200 cobalt sources that produce gamma rays and fancy software to deliver very precisely targeted doses (about 13 gray (a measure of radiation) at the edge-25 gray at the centre of the tumour) even to funnily shaped tumours. SRT involves usually 30 doses of less than 2 gray (this dose is chosen by cancer therapists as the normal cells can recover from that dose in 24 hours, the efficacy of treatment depending on the greater sensitivity of cancer cells than wildtype ones to the radiation). Each dose would be delivered every day over 30 days, not counting weekends. Targeting would not be as precise as with GKRS. The oncologist gave me a paper from the Heidelberg hospital that showed excellent results with SRT, in which the amount and severity of side effects was lower than with GKRS. I was impressed with this paper and formed the opinion that I should go for SRT. I wasn't worried about doing something over 30 days, as although this was inconvenient what mattered was effective treatment, and also I was hoping to keep my hearing. I did have some worries about SRT however, arising from my reading and discussions with others by mail, especially the Sheffield specialist, who pointed out to me that theoretically SRT shouldn't work on AN because as they grow so slowly there should be little differential sensitivity to radiation. As a biologist I knew experiments are more reliable than theory, so I wasn't too worried by this. However I was concerned about the precision of targeting being lower with SRT than with GKRS (in which a helmet is screwed into the skull to make sure nothing moves, and the precision is ca 0.5mm, as against 1-2mm for the SRT). Although the Heidelberg records were good, some other hospitals had less success, and the linear accelerators used were varied and might vary in precision and evenness of spread of dose delivery.

The oncologist advised I should seek help in choosing between the two forms or radiation treatment and sent me off to the gamma knife expert.

Consultant 3 The Gamma Knife Expert

My meeting with the gamma knife expert, in Harley Street was only 15 minutes, although I didn't know this at the beginning, so it was perhaps unfortunate for me that he did his PhD in our lab years ago and much of my expensive interview was spent reminiscing. However it was his opinion I wanted, and he advised GKRS, it had a longer record, made theoretical sense and was more precise. He treats people at the Cromwell in London. I therefore left there with the plan to do GKRS!

A new thought

However I was now wondering whether to check whether my AN was growing before treatment. The neurosurgeon had written to me advising me "not to have GKRS until there was documented growth" and I knew that follow up studies for as long as 3 years on untreated ANs were showing that some 60-70% of the things were not growing. There were even estimates that 5-10% of these aliens actually get smaller on their own! There was also the interesting matter of frequencies: the proportion of the population who go to doctors with symptoms was about 12 per million per year, but the incidence of ANs, estimated from the growing number of MRIs being done for all kinds of other reasons, was 700-800 per million. This seemed to mean that a lot of ANs didn't come to the notice of doctors at all. Not only that, I didn't have much in the way of symptoms, my dizzy spells and even my tinnitus were going away, and I began to suspect I would be worse after any kind of treatment, and therefore wondered if I could delay it so I could continue to enjoy my present quality of life for longer. I asked the gamma knife expert and he said he thought I should have the treatment directly, it hadn't got to that size by doing nothing and there was a good chance it would grow more and cause trouble.

So now I have seen 3 consultants and I have made 3 decisions, all different. I have been reading papers and have learnt more than I am writing here. But I noted that each consultant favoured "their" treatment, that my tumour seemed ideal for all three and each felt confident in their ability to treat me.

By now I was wondering where I should have the GKRS and in comparing the different Elekta machines I got in contact again with the Sheffield specialist, where they have an Elekta 4C machine (the nearly-latest version). I was impressed by his letter to me, and resolved to go and see him to discuss treatment.

The Sheffield Specialist

The Sheffield specialist is both a neurosurgeon and a gamma knife expert and had published a nice and encouraging paper on the AN cases in Sheffield. There is a GKRS centre there, it was the first one established in the UK. He is a cautious uncertain kind of doctor, the kind I appreciate. Too much confidence makes me insecure. After having looked at my scans he advised I should consider having no treatment until growth was monitored. And then, if it were growing, to have gamma knife, he showed me the precision they can achieve with the dose on the computer. GKRS involves two nights in hospital with treatment on one day.

So now its January 2007. I had my first scan in September 2006. In March it will be 6 months and I will have another scan and see if its growing. Fourth big doctor, fourth plan. I checked this plan with all 3 previous consultants and all have concurred it's a fair plan, even the gamma knife expert who seemed to change his mind on the need for immediate action.

Some matters that come up in discussions.

- The neurosurgeons argue that in most cases they remove the tumour and after a five year period the patient is discharged. This they say is a big advantage, as the radiation treatment does not remove the tumour and you know it is there the rest of your life, maybe going to wake up and do damage. You need periodic scans and psychologically this is not pleasant.
- However the radiation doctors point out that they find themselves irradiating patients who have come to them after failed neurosurgery and they say that the rate of recurrence after microsurgery is some 3-5% and this is the same rate of recurrence they get after radiation.
- The neurosurgeons riposte is that radiation follow ups are not long enough, particularly for patients who are young when first treated.
- The gamma knife people say the risks and damage to facial nerves are less than with neurosurgery, they point out the operation is much nastier for the patient than the irradiation.
- The neurosurgeons say that the irradiation damages the tissue so that operating afterwards is more difficult and more liable to damage. Having talked to a couple of other neurosurgeons my impression is that this is true, but its not clear how much of a factor in decision making this should be.
- The neurosurgeons point out that irradiation can make benign cells malignant,
- The radiation doctors say that numerically the risks are vanishingly small and the number of documented cases that are definitely due to the irradiation worldwide is only 1 or 2. This argument is probably more of a worry for young patients with many years to go, (the risk is constant per year).

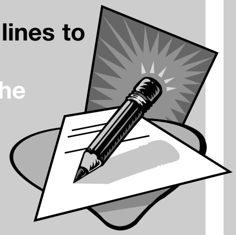
The most objective comparison between microsurgery and GKRS (a study of two groups of similar patients at the same hospital, one undergoing surgery, the other radiosurgery, followed up over a period of 1-5 years) was published last summer 2006 from the Mayo Clinic, it concluded much in favour for GKRS for all tumours less than about 2 cm, provided that nothing bad was going happen after GKRS beyond the 5 year follow up period, and this they couldn't be sure of, but it looks a fair bet that it won't. With this proviso they concluded "GKRS should be considered the best management strategy for the majority of AN patients"

Who knows if I have made the best decision, it is unknowable. In time I suppose I will know if I regret it. But my story shows how important it is to see various doctors and hear different sides of the argument. Treating AN is not really science, it's a mixture of craft and experience and crystal ball gazing. Since all the doctors now reiterate "the patient must decide" I think it helps the patient to get the various viewpoints, it certainly seemed to have helped me.

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
email: chris@richards2113.fsnet.co.uk

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

By: 11th May 2007

AMNET Advisory Panel at Addenbrooke's Hospital

Mr David Baguley MSc MBA
Principal Audiological Scientist

Kate Burton
Advanced Practitioner in Neuro-Oncology

Jean Hatchell
Clinical Nurse Practitioner

Mr Robert Macfarlane MD FRCS
Consultant Neurosugeon

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

Mr N J C Sarkies MRCP FRCS FRCOphth Consultant Opthalmic 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. There is a charge of £2.00 for all except for the first title.

Surfing the Net?

Next time you go surfing don't forget our AMNET web-page on http://www.amnet-charity.org.uk

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
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

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 a new booklet which is available from Alison at a charge of £2:
'Effects an acoustic neuroma can have on your memory, emotions, behaviour, executive functioning and energy'

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

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New Website: www.bana-uk.com

FORTHCOMING MEETINGS

Next meeting will be held on **Saturday 14th April 2007** in the **Boardroom** at **Addenbrookes Hospital.** The speaker will be **Rachel Rowlingson, Occupational Therapist who will speak about 'Coping with fatigue'. Doors open at 13.00 All welcome.**

Meetings later in the year will be held **on: Saturday July 7th 2007 Speaker ? Mr G C Cormack MA FRCSEd Consultant in Plastic Surgery at Addenbrookes Hospital, Cambridge.**

Saturday November 24th 2007 when speaker will be **Mr David Moffat Consultant in Otoneurological and Skull Base Surgery, 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.

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