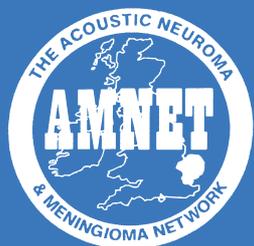


AMNET NEWS

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 2004
Issue 29

Skull Base Surgery at Addenbrookes Hospital

A talk by Mr David Moffat Consultant in Otoneurological and Skull Base Surgery
AMNET Meeting held on 6th December 2003.

Reported by Chris Richards



We were very pleased to welcome Mr Moffat to our Christmas meeting and he gave us an update on the series of skull base operations which have been carried out at Addenbrookes since 1981.

He highlighted the increasing emphasis on quality of life for patients which has developed over the last 10 years and much of the data collected from patients operated on in Addenbrookes has looked at the effects of surgery on the patient. This, as he pointed out is the *raison d'être* for organisations such as AMNET.

He began his presentation with a description and scan pictures of what an acoustic neuroma looks like and described how it is a space occupying lesion within the skull and it is the pressure caused by the growth of the tumour which leads to the symptoms suffered by patients when they present to their doctors.

Of the patients referred to Addenbrookes between 1981 and 2000 16% came from the Cambridge district, 46% from the Eastern Region and 38% from outside the region including a number from abroad. The cases coming from abroad were often unusual and difficult cases.

The majority of referrals come from other ENT surgeons and were usually patients with unexplained unilateral hearing or balance disturbance. Acoustic neuroma is a very deceptive condition as the tumour grows slowly into an existing space in the brain so it can become fairly large before it causes symptoms. If the tumour is impinging on the trigeminal nerve it may cause numbness in the face and loss of the corneal reflex, which is responsible for blinking and protects the eye. Later symptoms of an enlarging acoustic neuroma may be unsteadiness or headache, blurring of vision and swelling within the eye, which can lead to blindness. The last three are a result of increasing intracranial pressure. As the tumours only occur in 1 per 100,000 of the population most GPs will only see one in their working lifetime, so it is

often difficult for them to recognise the condition when a patient is complaining of mild symptoms.

The number of operations carried out at Cambridge has increased from 7 per year in 1981 to a peak of 74 in 1998. Numbers have fallen a little since then, mainly as a result of the wait, watch and rescan protocol which has been developed for patients with small tumours or who may be less suitable for surgery. This programme is giving a lot of information about the rate of growth in tumours and the symptoms they cause. At present it appears that 60% of these tumours have stopped growing. The other factor in the recent fall in numbers is the increase in patients having stereotactic radiosurgery such as the Gamma Knife.

The preferred surgical approach at Addenbrookes is the translabyrinthine approach as this allows the facial nerve to be seen from both ends which makes it easier to detach the nerve from the tumour. As this approach is through the labyrinth in the ear, the labyrinth itself is removed and fluids from the inner ear are released resulting in the loss of any residual hearing. There have been 663 translabyrinthine operations compared with 110 retrosigmoid approach operations. The retrosigmoid approach does save residual hearing, but as many patients have quite significant hearing loss or distortion, what is left is often not what can be classified as useful hearing. Hearing is not useful if it is less than 20% of that in the other ear. A guideline is that if patients are unable to use a telephone the hearing is not socially useful in that ear. The criteria is the ability to distinguish speech sounds. If hearing which is not socially useful is preserved it may result in being worse than having no hearing at all.

Next Meeting

Next meeting which will be our **AGM** will be held on Saturday 15th May 2004 in Boardroom at Addenbrooke's Hospital. Doors open at 13.00hrs and the AGM will commence at 13.30 hrs. Our speaker will be Mrs Ivy Court Manager of the Emmeline Centre for Hearing Implants



The patients at Addenbrookes have been evenly distributed between men and women with ages ranging from as young as 9 years to over 80 years. The bulk of patients are in their 50s or 60s with an average age of 53.6 years. For the younger patients there is a need to be aware that the tumour may be a result of NF2 (Neurofibromatosis), a hereditary condition in which neuromas may occur on both acoustic nerves and also on other nerves in the body.

Tumour size showed that fifty percent had tumours over 2.5 cm. The outcome is likely to be better in smaller tumours so early presentation is important.

When examining the symptoms with which patients present to the team 77% patients present with hearing loss, 10% with tinnitus, 10% with imbalance, 3.5% facial numbness and 1.6% with headache.

Hearing loss - 87% of patients had progressive hearing loss, 2% had no hearing loss and 1% had fluctuating hearing loss. A further 10% had sudden loss of hearing and this is a result of compression of the internal auditory artery against the bone causing a lack of blood supply to the ear.

Imbalance – 30% patients were unsteady on their feet, 30% had no balance problems and 21% tended to veer towards their affected side.

Tinnitus – 10.2 % had no tinnitus, 53% had constant tinnitus and 22% had intermittent tinnitus. For 75% the frequency was high, for 15% it was medium and for 10% it was low. Mild tinnitus is tinnitus which can only be heard during the day when the ambient noise level is low, moderate tinnitus is that which can be heard during the day above the ambient noise of everyday life and severe tinnitus is severe enough to prevent patients from sleeping. Of the patients with mild tinnitus there is an 82% chance that it would stay the same or get better and only an 18% chance that it would get worse. Of patients with moderate tinnitus there was a 20% chance of it disappearing following the surgery and 68% chance of it staying the same.

Of the patients who presented **with tinnitus**: 2% of patients had severe tinnitus, 57% had mild tinnitus and 41% had moderate tinnitus following surgery.

Of the patients who presented **with no tinnitus**: 7% still had no tinnitus, 17% had mild tinnitus and 6% had moderate tinnitus. So there is a one in four chance of developing tinnitus after surgery and it is likely to be mild.

Of the patients who had **mild tinnitus** there was an 82% chance that they would stay the same or get better, and for patients who had **moderate tinnitus** there was now a one in five chance of losing it after surgery.

Some patients require the insertion of a shunt to drain fluid from around the brain to relieve intracranial pressure. The shunt drains fluid into the atrium of the heart or the peritoneum. This is sometimes necessary in patients with large tumours and may be more likely to occur in elderly patients with a small cerebellar-pontar angle.

The operation

History - Charles Anandale, a professor of surgery in Edinburgh was the first person to remove an acoustic neuroma in 1895, Charles Balance was the first to remove a meningioma even earlier. Harvey Cushing early in 1920

reduced the mortality rate of 90% to 20% by not attempting to remove the tumour, but debulking it and sewing the edges together. William Dandy, one of his pupils, was the first surgeon to remove an acoustic neuroma in its entirety

The average duration of operations at Addenbrookes was around 6 hours with a range between three hours and 16 hours. The median (mid point) length of stay was 12 days with a range between 5 and 171 days. Peri-operative mortality rate is less than 1%, and 17 patients have been admitted to rehabilitation with an average stay of 28 days.

Effects of surgery

Patients quality of life

Facial weakness It is technically difficult to dissect the facial nerve from the tumour – it fits against the tumour like a piece of cling film- and recovery of facial nerve function is dependent on a number of factors including blood supply. Measuring the effect on the facial nerve has been done using the House-Brackman Grading system. This grades from Grade I as normal function to Grade VI as total paralysis Grades I to III are regarded as good facial nerve recovery although Grade III has more recently been subdivided into 3a and 3b in order to take into consideration the result with regards to eye symptomatology. In tumours less than 1.5 cms there is a good facial nerve result in 93% of cases and 91% in tumours 1.5 to 2.4 cm.

In the Addenbrookes series 78% of patients with tumours over 2.5 cms were getting a satisfactory House-Brackman score.

Regeneration of the nerve takes place at the rate of 1mm a day and there are 25 cms from the brain stem to the face muscles so the process can take up to five months. Aberrant regeneration can lead to 'crocodile tears' on eating and metallic taste. 48% of patients will develop crocodile tears or metallic taste or both. Metallic taste will improve with compensation from the nerve on the other side of the face. In 5% metallic taste will improve over 2 years however the crocodile tears are unlikely to get better.

Vestibular status –Most patients who have normal balance will compensate for the loss of one balance nerve. People become unsteady when their balance system is stressed or in the dark but most recover in the first year.

Cerebro-spinal fluid (CSF) leak is a risk of any operation in the skull and occurred in 3% of the patients.

Hearing Handicap Index - when this is measured it shows that most patients have some hearing handicap before surgery but this does not get worse after surgery. Hearing may be preserved in a retrosigmoid approach but this often results in leaving a small part of the tumour.

Mr Moffat finished his talk here and then offered to answer questions.

Questions

Would results for facial nerve be better if operations were done in bigger centres?

Mr Moffat pointed out that there is now a system of surgical dovetailing. For all surgeons there is a learning curve which means that techniques and results can be improved over time in relation to the number of operations carried out. If a new

consultant works with an experienced consultant, as Mr Axon is working with him, they can work together over difficult cases and there will not be gap in the learning curve when an experienced surgeon retires. There is also discussion of rationalisation of treatment of rare conditions into a smaller number of centres to retain the expertise obtained with a high number of operations. This is of course dependent on other consultants referring their patients, (and possibly patients and GPs being aware of which are the centres of excellence and asking to be referred to them)

He also re-emphasised the importance of being aware of patients' quality of life when measuring outcomes to surgery.

Asked whether it is an **hereditary condition** Mr Moffat explained that research had shown that acoustic neuromas occurred when there was a sporadic mutation in both chromosome 22s in one cell. In this case it is not inherited and is unlikely to occur again. In young patients there is more of a chance that they are suffering from NF2 which is an hereditary condition and there is a mutation of chromosome 22 in every cell, so if a spontaneous mutation occurs in the other chromosome 22 this will cause a tumour which could occur on any nerve in the body, not just the acoustic nerve.

He was asked about the **evidence for mobile phones being a cause of tumours** to which he replied that there is no evidence -based link between mobile phones and cancer of the ear or other tumours, only time will tell. He also mentioned the way the press exaggerate this information and he feels that the press and sites on the internet often have their own drum to beat on a particular issue and this may not be based on medical evidence. It is better for patients to have an informed medical opinion before they go searching on the internet. He cited recent evidence regarding the risk of malignancy following radiosurgery and of poor results on the facial nerve in surgery following unsuccessful radiosurgery as examples of side effects which may not be publicised on some web sites.

A question about whether he was intending to write a book was answered in the affirmative – it will be when he reaches a target of 1000 patients

Bone –assisted –hearing-aids BAHA were also raised. Mr Moffat explained that those with single sided deafness (SSD), had two options they could either put up with it or use a CROS aid which will transmit sound from the affected side to the other ear. The BAHA consists of a titanium post embedded in the bone behind the ear on which a hearing aid can be attached and will enable sound to be transmitted to the good ear through the skull. There may be some problems related to risk of damage to the post particularly during activities such as sport. The costs are high - £8000 as surgery is involved to implant the post and there are also maintenance costs. Some patients may not find it suitable. It is possible to try out bone conduction before having the implant. Mr Moffat pointed out that the number able to obtain this on the NHS was limited as the Health Authority will only fund a limited number each year and there are many patients with SSD. At present there are still 2 or 3 private insurance companies who will pay but this will probably not last if the demand increases.

When asked about possibility of reoccurrence of the tumour Mr Moffat explained that reoccurrence will not occur if all the tumour has been removed. This may be the case when the tumour is stuck to the brainstem or if, on a retrosigmoid

approach it has not been possible to remove everything. There have been 4 patients with reoccurrence in the series of 900 at Addenbrookes and only one required re-operation.

Questioned about dealing **with severed facial nerve** Mr Moffat described the procedure during surgery which is to try and reconnect the ends using a tube of fascia (muscle) to hold them together and if this is possible a House Brackman Grade III can be obtained. If the nerve is intact they will wait 12 – 18 months to see how much recovery there will be. Facial reanimation is best done at about a year. A number of cosmetic procedures are possible including face lift, facial sling, tarsorophy and gold weights. Reanimation can be attempted through fasiohyperglossal anastomosis which takes muscle and nerve from elsewhere in the body or a cross facial graft which trains a nerve from the other side of the face. This can have good results but does involve 2 or 3 operations.

The problem of **memory loss** was raised and Mr Moffat suggested that removal of the tumour will disturb the normal anatomy and neurophysiology of the brain which may cause vivid dreams and affect memory, although memory does deteriorate as we get older. He says there is not enough evidence yet.

Balance problems in situations such as escalators was discussed and Mr Moffat suggested that fixating on a spot while moving, as ballerinas do while pirouetting helps the vestibular system cope with sudden or difficult motion.

Mr Moffat finished after spending two hours with us, so we would like to thank him for giving his time and for a very interesting talk and we look forward to his next visit.

We would also like to thank Graham Allcock for taping the talk so the tapes will be available to members who were unable to attend.

Editorial

Hello everyone

Welcome to our Spring newsletter. I hope you will find things of interest to you. We have the report from Mr Moffat's talk to our Christmas meeting – Alison also has tapes of the meeting if anyone who missed it would like to hear it. We also have more information from the Conference held in Cambridge last year, information on Bone Assisted Hearing Aids and some travel tips

We look forward to seeing as many as possible of you at our AGM and please consider whether you could help the committee at all as it is important to have new people involved with the running of the organisation.

We are also looking for more people willing to be contacted by phone. If people are interested we will arrange a workshop so they can find out more.

So I hope we are all looking forward to a warm and sunny summer

Best wishes

Chris.

Fourth International Conference on Vestibular Schwannoma and other CPPA Lesions Cambridge 13th – 17th July 2003

This conference which included all the leading professionals in skull base surgery was held in Cambridge last summer. Unfortunately we were unable to be there in person, but Mr Moffat has kindly provided us with a copy of the Conference Proceedings which includes summaries of all the papers and posters presented at the conference. This makes interesting reading and I have endeavoured to extract a flavour of some of the important issues which were discussed.

As the introduction suggests although there are many papers covering surgical techniques and unusual case studies, there was a growing interest in stereotactic surgery, conservative treatment and quality of life of patients post surgery.

There were some reviews of series of patients who had been treated with Gamma Knife or LINAC. Some of these reviews were on quite small groups of patients but a couple of studies reported series of over 230 patients. The overall findings seem to suggest that in at least 75% of patients the tumour reduces or stays the same size – some studies give tumour control rate of over 90%. The rate quoted in one study for tumours which may require further treatment is between 1.5 and 10.5%. These studies also suggest around 75% of patients have hearing preservation and with decreased doses of radiation over the last 5-6 years the incidence of facial weakness is much reduced. On the other side there is a study which suggests that if further surgery is required the prognosis for facial nerve outcome is poor – over 50% were worse following surgery. So it appears that while there are still concerns regarding this approach to treatment it is becoming more common, particularly in patients with smaller tumours.

The other big issue at the conference was the increasing use of conservative management for some tumours. A number of centres reported series of patients who had been treated as 'watch and wait' over a number of years. In a study of 100 patients over 10 years only a third of the tumours had exhibited growth which required intervention, in another study of similar numbers over 3 years 47% patients showed significant growth of the

tumour but only 20 % required treatment. Research seems to suggest that smaller tumours are less likely to grow and that rate of growth is not related to age. Studies did however note a deterioration in hearing over the period of observation.

Quality of life in patients who have had treatment for acoustic neuroma has been investigated. Using some standard questionnaires the impact of surgery was investigated. One study found that there was no relationship between age and facial nerve dysfunction, hearing loss, or general health in the patients who had undergone surgery. A study carried out on 200 patients found that although surgery may be inevitable, conservative management may delay the effect on health and function resulting from surgery, giving patients longer before surgery becomes necessary. Most studies looking at quality of life in patients who had undergone surgery found that their quality of life was worse than that of the general population, particularly emotional and social aspects of life. Research has also suggested that the effect on quality of life is not clearly related to facial handicap or tumour size, but that those with a personality more prone to depression are more likely to have a worse quality of life following surgery. It has been suggested that patient's personality and attitude towards life should figure in decisions about whether to operate or treat small tumours conservatively.

It is encouraging that there is work going on which takes a view on the patient's perspective and may influence the way acoustic neuromas are treated in the future.

CAMTAD Cambridge Campaign for Tackling Acquired Deafness

The latest newsletter from CAMTAD includes an extensive list of places in Cambridge and some surrounding areas which have a loop system or hearing aids. They are also asking for volunteers who have good eyesight and normal use of their hands to help at monthly Hearing Help Sessions.

Further information on either of these topics available from Sue Hempstead at 8A Romsey Terrace, Cambridge CB1 3NH or Tel 01223 416141

Christmas Meeting



This photo shows members enjoying the buffet at our Christmas meeting on December 6th 2003

Meningioma Association UK

Our contribution from Ella and Caroline this time is information on travel insurance which I'm sure we will all find helpful

Travel Insurance Tips

The main issue for anyone with a meningioma travelling solo or with their partner or family is to find a travel insurer who accepts medical conditions. Pre-existing medical conditions are one of the most important exclusions in all travel policies unless they have been disclosed when taking out the policy and have been approved by your insurer. Some companies won't cover pre-existing illnesses at all, and others increase premiums or excesses.

Don't buy it with your holiday! Shop around for travel insurance. There may be a marked difference in charges between companies. Take a look at WHICH magazine published by The Consumers Association and generally available in your local library or online: WHICH surveys the travel insurance market in March each year and pays special attention to people with pre-existing medical conditions. Save yourself time by asking your local insurance broker, or AGE Concern Travel Insurance who claim they insure any age, or RIAs, the Retirement Insurance Advisory Service (for over 50's)* to find the holiday cover you want at the best price. When telling your insurer that you have a meningioma emphasise that this is a benign brain tumour. It is vital to tell the insurer about any pre-existing medical conditions otherwise these won't be covered if you make a claim.

Be prepared for questions - you may be asked for the dates of your last and next hospital visit, what they

were for, and also about any proposed or ongoing treatment. For instance, if you are booked for surgery within a short time, you will pay more than when it has been inactive for a long time and no other treatment is proposed. You may be required to provide a letter from your GP or your consultant indicating that you are fit to travel. This is particularly relevant for people with a newly-diagnosed meningioma or who have had recent treatment.

Travelling in Europe? Do take your E111 as well - insurers may waive excesses for medical treatment if you use your E111 to get treatment. Possession of a valid E111 form acts as a document of proof that you are entitled to free or reduced cost emergency medical treatment within the European Economic Area (EEA). E111 forms are free to all residents of the UK; they are widely available at all Post Offices throughout the country. An E111 is not a substitute for travel insurance, and should not be considered as a cheap alternative. It provides cover in an emergency, and is only valid in EEA countries. For complete coverage you should always take out your own travel insurance policy as well.

France and the E111 Beware that French health authorities are unlikely to accept an E111 as valid unless it is within 12 months of its date of issue, notwithstanding the 'infinite validity' on UK documentation.

Subtitles

While at the CAMTAD Exhibition I picked up a leaflet from the BBC about subtitling which I thought some of you may find interesting

The BBC has been providing subtitles for its television programmes since the early 1980s. They are designed principally to help the estimated 8.5 million people in this country who have some kind of hearing loss. Subtitles sit at the bottom of your television screen, reproducing the soundtrack of the programme as closely as possible. At present more than 80% of BBC One and Two programmes are subtitled and the new digital channels such as BBC3 and BBC 4 are catching up fast. By 2008 all programmes will have subtitles. Almost all prime-time television programmes on BBC One and Two are now subtitled, including live programmes and events such as sport.

On an analogue television subtitles can be obtained if your television has teletext. By pressing TEXT on your remote control you get to Ceefax and if you type 888, if the programme is subtitled the subtitles will appear on the screen. If you have a digital television if you select SUBTITLES on the Set-up menu the subtitles will automatically be on screen whenever you turn on - you can turn them off again by using the SUBTITLE button on your remote control.

In order to subtitle a programme the subtitler first watches a tape of the programme, listening to the soundtrack in short sections. Using a specially designed computer, he or she

reproduces the soundtrack as short easily read subtitles. This text is as close to the original as possible, but usually has to be edited slightly to allow the viewer time to read the words and watch the picture. The subtitles must also be carefully timed to ensure they are synchronised with the speech.

If the programme is live, the subtitlers are joined by a team of stenographers who transcribe what is being said as it happens. This takes nerves of steel: many of the stenographers can type up to 220 words per minute and although there is the odd inevitable mistake, they pride themselves on an accuracy rate of 97%. They are also experimenting with speech recognition software which have been used to produce subtitles for a number of recent sporting events.

Sometimes subtitles may appear incomplete or jumbled and this is because the quality of television reception varies from area to area and this can affect subtitles. If you notice missing letters or see strange symbols, your television set may need adjusting. The atmospheric conditions in your area may also affect the service.

If you need advice about reception you can write to: BBC Reception Advice, Room 220, Design Building, Television Centre, Wood Lane, London W12 7RJ

New Hope for Single Sided Deafness

Ian Johnson MD FRCS, Consultant ENT Surgeon, The Freeman Hospital, Newcastle, reports on a new device.

Taken from Hearing Concern Magazine Summer 2003

Unilateral hearing loss of Single Sided Deafness (SSD) refers to either complete or significant hearing loss in one ear. Last year, the second stage of a research project to establish the benefits of the bone-anchored hearing aid BAHA to people who have SSD in the UK was completed. This research was funded by Entific, a Swedish company which specialises in hearing and facial rehabilitation systems.

The findings show that many people live with a wide range of problems as they struggle to cope with the loss of hearing in one ear. Many find the loss of stereo effects derived from hearing with two ears, leaves them with an 'acoustic shadow' such that sound originating from their poor side is missed. This is particularly noticed at meetings or out in a restaurant when someone persistently talks from one side. There are also problems of sound localisation, making it difficult to determine the origins of noises; not only is this socially embarrassing but it can present dangers when out alone in determining the direction of traffic. Indeed over half the people in our study experienced difficulties when out as a pedestrian. Worryingly, many also found SSD has affected their ability to work – in some cases to the extent that they have either had to give it up, move to lighter work or go part time.

The BAHA provides a unique benefit to people with SSD by enabling the user to hear and understand sounds from both sides of the head whereas before they could only understand sounds from the direction of their good ear. Previously the treatment options were limited; a minority of patients derived some benefit from a high powered conventional hearing aid,

but their numbers were small. A CROS (Contralateral Routing of Sound) aid can relay sound from the affected side to the good ear, but many people dislike wearing hearing devices on both ears.

A bone-anchored hearing aid (BAHA) can restore the sensation of sound from the deaf side. This type of aid has been available for over 25 years for all traditional bilateral conductive hearing loss indications and over 11,000 people have been treated with BAHA worldwide. BAHA received Federal Drugs Administration (FDA) approval for the treatment of Single-Sided Deafness in 2002 and to date 400 patients with SSD have been treated using BAHA in Europe and the USA.

At present BAHA is available on the NHS and privately. Once in the secondary care system (hospital), patients with SSD receive the same priority for treatment as patients with bilateral deafness and will join the same waiting list for treatment as patients with bilateral deafness. Ideally, eligibility for treatment of SSD should be partially assessed on the extent to which SSD is a disability. Therefore consultants and surgeons may rely on patients to articulate the scale and severity of their own disability; treatment is not necessarily recommended for all.

If you would like to learn more about BAHA and its potential benefits as a solution to SSD, please contact your local hospital or ENT consultant or visit www.entific.com or www.patient-baha.com.

How BAHA works

The BAHA device works by conducting sounds from the deaf side through the bone of the skull to the hearing ear. The brain is then able to distinguish the sound that it receives through the hearing ear via the BAHA device, from the sound that it receives directly from the hearing ear. This ultimately results in the sensation of hearing from the deaf side. The BAHA device has two main parts – an external sound processor and a small titanium implant, which is placed in the skull bone behind the deaf ear. The sound processor transfers sound to the titanium implant and in this way, the vibrating sound waves become directly connected to the skull.

The sound waves then travel through the skull bone to the inner ear on the hearing side. Minor surgery is needed to fix the implant and patients leave hospital the same day.

The external sound processor clips on to a small abutment, so it can be easily removed and the whole device is hidden by hair.

AGM

Our AGM will be held on **Saturday 15th May at 13.30hrs** in the Boardroom at Addenbrookes Hospital. Committee members who need to be re-elected are chairman, secretary and treasurer. If anyone would like to be nominated or wishes to nominate anyone for these posts, or has items for the agenda, please contact Alison Frank (Phone number on back page of newsletter). Please also consider helping us on the committee – new blood is very important for the growth of the organisation.

Agenda for AGM

Apologies
Minutes of last meeting
Chairman's Report
Treasurer's Report
Election of officers
Any other business

Rachel's Corner

Saving Face

Rachel Pearson has met Rod Franks and she thought we would like to hear about his experience.

Before surgery we all view the prospect of facial palsy and the loss of hearing on one side with trepidation. It is rarely quite as devastating as it was for Rod Franks, Principal Trumpet with the London Symphony Orchestra. Music had been a driving force in his life since the age of six. He was only 46 when acoustic neuroma was diagnosed in 2002.

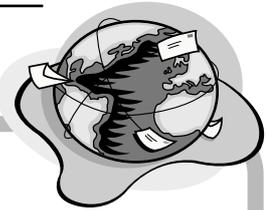
Immediately after the surgery his embouchure was intact but a month later facial palsy set in. This was a huge blow. However with steroid treatment there was gradual improvement. At first all he could do was blow single notes. Gradually he managed scales and with incredible courage and perseverance reached professional playing standard again.

With the aid of a digital Cros aid specially invented for him he copes with the demands of orchestral playing despite tinnitus and headaches. He is so grateful to the surgeons and their team at his London hospital that he has raised a large amount of money to help their work with acoustic neuroma patients.

He has produced a splendid CD, the profits from which go entirely to the Friends of Guy's and the LSO sickness and benevolent fund, which helped with the cost of the hearing aid. The music includes both Baroque and jazz, ranging from Lully to Richard Bissell. All is melodious and a joy to listen to. The musical quality is superb.

To order your CD, telephone 0207-367-6580. Available by mail order only. The code is CD DOY 148 and the title is Saving Face. Price: £12.95 post free. If you have any difficulty please contact Rachel, who has some spare copies.

postbag



This letter from Pauline offers a suggestion for a different approach to dealing with symptoms following surgery

Hopton-on-sea, Gt Yarmouth

Dear Editor

I am writing because I thought my experiences might be of help to others.

I have just moved from a large four bedroom house to a bungalow. I struggled to cope with the house after my op seven years ago for the removal of a meningioma, it left me with a facial palsy (which I still have), deafness, balancing problems and weakness down one side. I became depressed and lacked energy so my doctor prescribed anti-depressants and also suggested counselling might help.

I tried homeopathy for about nine months, but to no avail and cranial osteopathy which did help the tension in my body, especially my neck, but not my head.

Eventually I decided to give counselling a try. To date I have had eighteen sessions, I am so glad I did, it has made me a much more positive person. I never realised I had such a negative attitude. I understand myself so much better now. I no longer feel suicidal and can look forward to the future. The bungalow is the icing on the cake.

My energy levels are much improved, if I have a no energy week I don't let it get me down, as I once would. I know it won't last.

One thing does puzzle me, I have been unable to cry since the operation. I did write to my consultant for his opinion, but he could offer no explanation, except to say it would account for my lack of tears on the palsy side. My counsellor thinks it is something I'm blocking. There have been many occasions when crying would have been such a relief. I wonder if any other members have experience of this. I would be interested to know.

Yours sincerely
Pauline Goff.

Surfing the Net?



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

Anything from a few lines to a couple of pages

It all helps to make the newsletter more interesting.

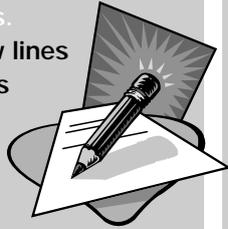
Contributions on paper and/or disc (Microsoft Word) to:-

Chris Richards

12 Sudeley Grove, Hardwick
CAMBRIDGE CB3 7XS

email: chris@richards2113.fsnet.co.uk

by: 29th May 2004



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

Addresses and Web sites

Addenbrooke's new website
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
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.

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>

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 next meeting will be the AGM and will be held on Saturday 15th May 2004 in the Boardroom at Addenbrookes Hospital. Doors open at 13.00 hrs and the AGM will be at 13.30 hrs. Our speaker will be Mrs Ivy Court Manager of the Emmeline Centre for Hearing Implants.

The following meeting will be Saturday 24th July 2004 at Addenbrookes Hospital when the speaker will be Laura Skorupa Information Officer from the RNID

The Christmas meeting this year will be held on Saturday 4th December 2004 speaker to be arranged.

The Meningioma Association UK

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

Tel: 01787 374084

Email: MeningiomaUK@aol.com
Website: 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

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.

Chairman	Secretary	Treasurer	Newsletter Editor	New Patients Officer	AMNET Librarian
Alison Frank	Tony Monk	Joanne See	Christine Richards	Neil Bray	Ray Maw
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