

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

Summer 2005
Issue 33

Recent Research in Cambridge

A talk by David Baguley

Consultant Scientist Hearing and Balance Group in Cambridge

Reported by Chris Richards



David introduced himself as a hearing scientist and director of the Hearing and Balance Group at Addenbrookes Hospital. He has worked at the hospital since 1985 and his main interests are in neuro-otology and tinnitus.

He explained that tinnitus is a real problem to many people and treatment has not always been effective. He said he was pleased to talk to the group who have been supportive of his work by giving time and resources and have been willing to help with research.

He described some of the changes which are taking place in the neuro-otology department at Addenbrookes. Mr David Hardy who was one of the pioneers of skull base surgery in Cambridge is retiring and his place will be taken by Mr Robert Macfarlane who has been working alongside Mr Hardy for a number of years. This has allowed the skills to be dovetailed in the passing on from one surgeon to another. This is also happening in the ENT department with Mr Patrick Axon working alongside Mr Moffat.

The objective of David's talk was to describe some of the recent research which has been undertaken in the department and he first addressed the question of why research was done. He suggested three reasons; to be able to do things better as we do not have all the answers; to raise the profile of vestibular schwannoma (acoustic neuroma) and meningioma issues such as hearing loss, tinnitus, facial nerve problems and psychological issues; and to take a holistic perspective of the whole person not just the tumour. There is a growing understanding that teams are dealing, not just with tumours, but with people and that the journey patients have made should be honoured. There is a recognition that people's experience should be considered and this may be more wide ranging than just the surgery.

Vestibular schwannomas (VS) grow on the vestibular nerve, developing in the Schwann cells which form the lining of the nerve. The tumour grows into the cerebellar-pontain angle, and if it becomes very

large it may touch the brain stem which could be life threatening. To prevent this happening tumours often require surgery.

Research has looked at auditory handicap and vestibular schwannoma. Research in America (Rigby et al 1997) looking at pre and post operative measures of hearing loss suggested that hearing loss was the most troublesome post operative symptom, but that hearing localisation improved after surgery. Research carried out in Nottingham by Bateman et al suggested that 72% of patients reported post-operative auditory dysfunction and that overall post-op disability largely related to auditory impairment – hearing loss was an important driver of how disabled people felt. Recent research has been carried out in Cambridge (Humphriss et al 2004) with 119 people using the Hearing Handicap Inventory pre surgery, at intervals of three month and 12 months post surgery. This showed that hearing handicap is variable, significant and tends not to change following surgery. Some of these people had severe hearing handicap before surgery. It is hoped the research will help the team to distinguish which patients are likely to be worse after surgery so they can receive appropriate counselling and therapy before surgery. The study also investigated the change in tinnitus after surgery. This showed that for the majority of people (87%) tinnitus remained the same after surgery and in a small number it either improved or got worse. It is important to tell patients that tinnitus is likely to stay the same and also to try to identify those for whom it will get worse. This group is linked to the group who suffer greater hearing loss.

Next Meeting and AGM

The next meeting will be on **Saturday 23rd July** at **Addenbrookes Hospital** in the **Boardroom**. Doors will open at 13.00hrs. The speaker will be **Chris Richards** who will talk about her research project **'Getting on with life' An interview-based study of the experience of undergoing and recovering from skull base surgery**. Members will be invited to discuss issues arising from the study and their own experience.



Another study in Cambridge (Baguley et al 2005) has been examining the change in tinnitus handicap following VS surgery. David described 'gaze modulated' tinnitus in which the level of tinnitus is vastly changed by moving the direction of gaze and 'somatic modulated' tinnitus in which the level of tinnitus changes with movement of the face, head or neck. The study showed that in general 60% of patients had tinnitus pre operation and for one in ten it was what had sent them to the doctor, that gaze modulation and somatic modulation are relatively common (19% and 14% of patients respectively) and gaze modulation is more common in young patients. It is thought that there is a connection between hearing sensitivity and hearing movement and gaze which is an inbuilt need to respond to danger which can still be seen in animals moving their ears or heads in response to sound. These links are normally inhibited in humans as they are they are no longer required, but when hearing is lost the tinnitus is unmasked.

The questionnaire also highlighted that 40% of patients complained of increased noise sensitivity which persisted after surgery. David quoted some research which suggested that although many people were medically fit to return to work after surgery about half of them did not return. This raises questions about some of the other factors which may influence this such as tolerance of noise in the workplace.

Another study which has been carried out in Cambridge has looked at medication which may help tinnitus. It has been known that a local anaesthetic called lidocaine can inhibit tinnitus if it is given intravenously, however the effect is transitory and there can be very serious side effects. The study examined whether the effect of lidocaine was in the ear or in the brain and used patients who were post translabyrinthine vestibular schwannoma surgery. The study showed that in the 16 patients – twelve men and four women, 75% of them had a reduction in the loudness, pitch and distress caused by the tinnitus, 12.5% (2 patients) had increase in loudness, pitch and distress and another two patients showed no change. The study suggested that the drug was working in the brain not the ear and it is hoped that work can be done with a drug company to design an oral drug which will reduce tinnitus.

What to do about tinnitus

David also talked about approaches to dealing with tinnitus. He described tinnitus as provoking very emotional reactions and suggested this is related to the body's response to any new sound which is intrusive and worrying. The brain responds to this sort of sound very quickly making people restless, alert and often anxious. Tinnitus retraining approaches are aimed at dealing with this response.

Suggestions for helping to deal with persistent tinnitus include finding out as much as possible as knowledge can only help. The British Tinnitus Association produces good handouts. Getting an informed and positive medical opinion will also help. There are a number of devices which can help with sound enrichment as for many people tinnitus is worse in silence. These devices include the pillow noise generator and the environmental generator which may be provided by the hearing clinic. Special hearing aids or noise generators worn in the ears can help with avoiding silence and reducing the effect of tinnitus.

Relaxation exercises which help to reduce agitation which may also help, as can addressing sleep problems. A leaflet on Sleep Hygiene called 'Good Night, Sleep Tight' is available from the British Tinnitus Association (www.tinnitus.org.uk). Other aids are available from the RNID on line shop (www.rnid.org.uk)

The role of partners and other family members is important. Tinnitus has been demonstrated to be associated with increased family stress and tinnitus distress can have a corrosive effect on relationships. It is helpful if partners accompany the person with tinnitus for appointments and read information so they understand more about the condition. They can be encouraging and offer space and support as well as assisting with relaxation.

David closed his talk by suggesting that the best is yet to come in terms of dealing with tinnitus and he hopes that there will be a good treatment, possibly a combination of drugs, counselling and sound therapy.

A lively question session followed including questions about the relationship between radio and mobile phones and tumours, for which David suggested that the evidence was not convincing on either side of the argument at present.

There was a discussion of the similarities with phantom limb and tinnitus and the ability to use thought processes to 'still' the tinnitus. David likened this to forms of meditation which can also work in controlling tinnitus.

There was some discussion about changing needs of people with vestibular schwannoma and with the 'watch and wait' policy patients will still need support for their symptoms of tinnitus and hearing loss while they are in this programme.

There was a question about whether having single sided deafness meant the other ear was more susceptible to hearing loss. David said this was not the case but it was still important to protect the good ear from noise-induced hearing loss by taking sensible precautions such as being aware that hearing is more susceptible when intoxicated, and that all noise is harmful whether it is a noisy concert or a household tool. It is important to take time out from noise in social situations and special earplugs can be obtained costing about £10 - £12.

We would like to thank David for a most interesting and enjoyable talk and send our best wishes to all in the department – especially Mr Hardy who is retiring.

References

- Baguley D, Jones S, Wilkins I, Axon PR, Moffat DA 'The inhibitory effect of intravenous lidocaine infusion on tinnitus after translabyrinthine removal of vestibular schwannoma: a double blind, placebo controlled, crossover study', *Otol Neurotol* 2005 Mar;26(2):169-76
- Humphriss RL, Baguley DM, Axon PR, Moffat DA 'Change in hearing handicap after translabyrinthine vestibular schwannoma excision', *Otol Neurotol*. 2004 May;25(3):371-8

Minutes of AMNET AGM held at Addenbrookes Hospital on Saturday 7th May 2005

Apologies: Ella Pybus, Fiona Pike

Minutes of the last AGM were read and accepted as a true record

Chairman's Report

Alison gave us her report for the year:

'Another year rolls by and AMNET has moved steadily on with few new members joining us and lots of enquiries. At the last AGM we had a fascinating talk about hearing implants from Ivy Court, the retiring manager of the Emmeline Centre. She has been involved with AMNET right from the start when I tried out ideas for a support group on her. Ivy was enthusiastic so I took it further. We wish her a long and happy retirement.

In July we had a talk from Laura Skorupa, an information officer for the RNID. Laura talked a little about her job and the problems people faced living with tinnitus and balance problems.

Our Christmas meeting was fun as usual with two complementary therapists Lynne Hitchin and Elizabeth Houghton. We were entertained by and instructed in Indian Head Massage and Iridology – the study of the iris of the eye. We thank all these people for sharing their time and expertise.

Over the last year we have managed to raise quite a lot of money which we want to use for the benefit of patients both in Clinic 10 and on A3. We have asked for ideas from Louise Marvis A3 sister, Jean Hatchell, David Baguley and David Moffat. A3 would like some laminated sheets with instructions for eye care and the two Davids are thinking!

We have strengthened our links with the Meningioma Association UK and helped them with a survey for UKBTS – United Kingdom Brain Tumour Society.

We are always planning ahead and hope to celebrate our tenth anniversary next year with something special. If you have any ideas for speakers or subjects you would like to hear please let us know.

Many thanks to all the officers and helpers who have kept AMNET going for another year.'

Treasurer's Report

Income 1872.03 Expenditure £2118.49 so there was a shortfall of £246.46. There is still £4284.50 in the bank and there has been a reduction in expenses this year due to reduction in membership and number of newsletters being produced. £500 each has been offered to Ward A3 and Clinic 10 at Addenbrookes to buy equipment.

Election of Officers

Chair – Alison Frank

Proposed by Joanne See, Seconded by Phil Mayhew

Treasurer – Joanne See

Proposed by Jill Laurimore, Seconded by Thelma Pye

Secretary – Tony Monk

Proposed by Eleanor Monk, seconded by Neil Bray

Other committee members:

Chris Richards

Newsletter editor

Neil Bray

New patient co-ordinator

Ella Pybus

Meningioma Association UK

Jill Laurimore

Eleanor Monk

Thanks also to: Thelma and Bill Pye for newsletter distribution

Margaret Allcock Trophic stimulators

Graham Allcock – recording meetings

Newsletter

Chris reported that she was still looking for any articles for the newsletter to make it everybody's newsletter.

Chris had been carrying out a research project with members of the group and she will report the findings at the next meeting.

Other business

David Hardy is retiring – AMNET sent their best wishes for his retirement in a card.

The committee raised the point that they have all served for a number of years and feel that they in danger of getting out of touch with present care for acoustic neuromas and meningiomas. As the membership had not been growing and there has been no new blood on the committee it may be necessary to consider the future of AMNET after our 10th Anniversary next year.

Editorial

Dear All

This is our summer edition but as I write this editorial there is little evidence of the sun – I hope by the time this lands on your mat things will have improved!

This time I have rather monopolised the newsletter as there is the report on David Baguley's very interesting talk and I have also included an article on my research project which some members helped me with. I have written this before I talk about it so that members can think about any questions or issues they would like to raise in relation to the project before the meeting. There is also a short article raising some questions about the future of AMNET and I would ask you all to read this and let us know your thoughts

Looking forward to seeing people at the next meeting on July 23rd and I hope we will all be enjoying a warmer summer by then!

Best wishes

Chris.

'Getting on with life' An interview-based study of the experience of undergoing and recovering from skull base surgery.

by Chris Richards



As the final part of a post graduate degree course I have been undertaking I was required to undertake a research project. When I was thinking about the topic I would like to study the idea of doing something related to acoustic neuroma was one possibility. I decided I would like to do a study examining the experience of people who, like me, had undergone surgery to remove an acoustic neuroma.

Research carried out on how people deal with illness and disability in their lives suggests that individuals in this situation have to deal with not just the change in their bodies due to illness, but also a change to their perception of themselves and how others see them. They often develop strategies to help them present this changed perception of themselves to those around them. My research identified some of the strategies the group of people I interviewed had adopted in order to deal with what had been a significant event in their lives.

The participants for my study were recruited through an invitation in the AMNET newsletter asking for volunteers to be interviewed for a research project. There were a number of volunteers of whom seven, three men and four women, went on to be interviewed. The content of the interviews was analysed to try to build a picture of the experience of the participants and the strategies they had used to deal with what had happened to them.

I identified two phases in the accounts given by the participants the illness experience describing how the problem was discovered, the experience of waiting for surgery and the effects of the surgery, and the recovery experience describing the strategies used to deal with the consequences of the surgery

The Illness experience

Discovering the problem

The way in which participants realised something was wrong and presented to a doctor varied. Some of them could trace hearing loss symptoms and headaches back a long way, sometimes years before the diagnosis was made and establishing a diagnosis was often difficult sometimes resulting in the participants being sent away as a problem could not be found or with a diagnosis of suggesting it was due to stress.

'I knew there was something wrong so I went down to the local doctors. I wouldn't say they fobbed me off, that would be incorrect, but sort of said 'How old are you? Oh yes you've got some wax in your ears' and that's how it went on. And he said, I did actually have a hearing test and they said 'No we can't actually find anything wrong - you should be OK'. That sort of then went away and I thought they were obviously right.'

The actual diagnosis was usually traumatic and the participants described themselves variously as 'stunned', 'shocked', 'dazed' or 'gobsmacked'. The experience was also described as unsettling because of the medical language and terminology used (this from someone with medical knowledge), and some had not taken on the implications of what was being said to them. However there was a feeling that with diagnosis they had become someone different, a person with a brain tumour, and this influenced their interactions with those around them.

Waiting for surgery

The wait for surgery was often many months and some participants felt their lives were put on hold while they waited, despite the fact that they did not feel ill and the tumour was benign. One of the wives said:

'I think the waiting didn't help did it, for the operation? It built up more and more - his headaches got worse (...) under his very hard exterior there was times when he got tired, came home you know. I mean you are shell shocked, you think those sort of things happen to other people don't you.'

There was also concern about what would happen after the operation – concerns were around surviving the surgery, suffering brain damage and the possibility of a facial palsy. One participant described it as a 'leap of faith' as he was well before the surgery but did not know if he would be well after the surgery.

The operation

There were few specific memories about the operation itself apart from it being daunting. Two participants had suffered quite serious complications one - had cerebro-spinal leaks and had to return to hospital three times, another a blood clot in her lung and a post operative infection. Most were just relieved to get home after the surgery – but then found they had a different set of issues to deal with.

The effects of surgery

All the participants suffered unilateral hearing loss following surgery but other problems they reported were facial paralysis, loss of balance and headaches.

Facial problems usually centred around the eye which would not close fully and would not produce lubrication, so became very sore. Later, nerves would regrow – but this often prompted inappropriate responses so that the eye would run in hot weather or when food is chewed.

'(...)My eye has been a bit of a problem. Not that it's dry - I did have dry eye, but in this sort of weather I get, my eye runs like a tap, and my nose runs like a tap, and so I get blurred vision where it's full of tears all the time.'

'My eye is continuously seeping I call it you know, more so when I talk a lot and when I chew food.'

How the face looks is also often an issue and although paralysis usually improves over time it rarely totally recovers. This leads to a change in the way the participants perceive themselves and how they believe others see them

'I think the worst thing of all was, my worst fear was to have facial palsy, and of course I got it, plus I had the tarsorrhaphy (eyelid stitched) and so I looked like some ogress from God knows where. I remember when I looked in the mirror for the first time, I just nearly burst into tears and it was quite a shock.'

'I have emotionally found it extremely difficult that I have lost my smile. I used to be a very smiley person.'

'Yeh. Well I did actually (have feelings about the way his face looked). (...) And I am still aware that when I smile it is very lopsided (...) I would like to get that better.'

Even after 12 years one participant is still very aware that her face looks different and for others it was the awareness that they were unable to respond to people in the way they did before.

Hearing problems, including tinnitus, were often more intrusive on lifestyle than expected

'I would rethink it (having the surgery) because the hearing loss which I thought at the time 'Oh big deal you just lose hearing in one ear. You've still got another good ear'. It has been devastating. It really has.'

Hearing loss presented a number of problems particularly in work and social situations and led to a loss in confidence in some of the participants.

The recovery experience

The way in which participants described the recovery period highlighted their need to develop strategies to deal with the change in their appearance and the ability to deal with certain situations. The strategies used by my participants varied – some were very active in seeking help to improve their situation, others accepted their situation and tried to live with it. The active ones I identified as 'being pushy' in line with a phrase used by one of the participants. One woman became skilled in identifying NHS sources – practitioners and special clinics who may be able to help her. She obtained information through self help groups and the internet and became adept at persuading her GP to refer her to the various clinics.

'(I found others) with very, very good suggestions of health service professionals who might be useful to me. Now as a result of that - I have been quite pushy I suppose and have had referrals to places such as the (specialist hospital) where no-one else had thought of sending me to which has been very helpful to me.'

Two of the men, who were both in executive jobs, were not able to find the help they felt they needed through the NHS and one paid for a Bone Assisted Hearing Aid and the other paid for physiotherapy to improve the appearance of his face. One of the women used her private health insurance to get treatment for her eye earlier than was offered on the NHS.

The other man was active in his recovery in a different way – he charted his recovery on a daily basis and set himself regular goals to work towards recovery. He saw recovery as his responsibility.

One of the main difficulties described was coping with social situations including work. The hearing problems led to difficulties in communicating when there is background noise and often the participants were unable to tolerate noisy situations. The result of this was that they did withdraw from some social situations and professed to preferring a 'quieter life' now.

'I cling to the friends I have because they understand that I cannot cope with conversation for any length of time. I do not go out for activities with few exceptions ... not being able to hear and then straining makes my head ache. I live quite a solitary life. I am not particularly complaining about this because I have learned to cope with it but for somebody more gregarious than me it would be a huge problem.'

'I do find I have slowed down a lot. I don't like big social events and things like that.'

For those still working there were additional problems which also required strategies such as explaining to the people they were working with and being selective about some of the things they took part in.

'I don't go into groups. I tend to stand back now. (...) But when you are meeting clients or business acquaintances for the first time then I just then. (...) I tend to tell people and get it out in the open.'

'I explain to the children (in school) that I cannot hear against background noise.'

One woman was not keen to go back to work because of the problems she had experienced before her operation so she took up the option of early retirement.

'I thought I would go back to work, but as time crept on I thought 'Well I'm getting nearer to retirement – may not sort of thing. But I still used the phones a lot at work, but I did find it very difficult with the hearing loss, in meetings and there was a lot going on in the office at the same time – that was quite difficult. (...) so I went for retirement on ill health. (...)'

Support

Support in various forms was very important in the way the participants dealt with the situation. Information was considered very important in helping people to cope and in the early days most of the information had come from health professionals. However once they had been discharged from hospital they needed to find other sources of support. The self help group had played a major role for these participants both before and after surgery. A couple had attended a meeting with some members who had previously undergone surgery and found it reassuring to talk to people who had undergone surgery and come out on the other side. Regular meetings were seen as reassuring in seeing others who looked the same and had the same problems and as a source of information.

'You see what I really basically always look for is reassurance that I'm not the only one. That's really all I need. (...) Because when I did attend the AMNET meetings everybody had the same things to cope with and I went away thinking 'I'm not the only one' I know that anyway but it's nice to hear it.'

However one participant did suggest that although self-help groups have their place people do move on.

'In terms of the induction sessions both for people going in that was very good I thought, very helpful. Good to talk to people who had been there, done that and come out the other side. The post operative I'm not so comfortable on as I find it brings me back to it rather than just putting it behind me.'

However for most of the participants the self-help group had provided information and support and for some the opportunity to put something back.

Coping

The way in which the participants talked about how they had dealt with the situation they had found themselves in highlighted a need to 'get on with their lives' Although they had to deal with changes in their self perception and identity this was a price they paid to get their lives back

'About my face? Well obviously I still feel a bit upset about it but I've got my life back. You know that's the big positive thing isn't it? (...) With my face? I ..well how does one deal with it .You just get on with life don't you.'

'I mean I cope with it because I have no other options, (...) I don't really linger on it. I just get on with things - don't I (to husband).'

'(...) but I'm a relatively positive person when it comes to things like health, whether it's mine or the family's I don't like to think - I'm not one 'Oh God this is the end of the world' sort of thing. I just sort of get on with it.'

Conclusion

The way my participants responded to the situation of undergoing skull base surgery had a number of similarities with the way other research depicts response to serious and chronic illness. An episode such as this disrupts our lives and we have to deal with that change and incorporate it into the way we see ourselves and our perception of how others see us. I felt that my participants had in general managed to do this and the strategies they had developed for coping with the changes have, over time, allowed them to 'get on with their lives'.

I would like to thank the participants in my study for giving of their time and of themselves generously to allow me to complete the study and to the volunteers whom I did not manage to interview. I would also like to thank the AMNET committee who supported my efforts.

Where to now?

AMNET is nearly ten years old and at the last committee meeting we were discussing how to celebrate this. We are hoping to mark the anniversary with an exciting event, however this forthcoming milestone also raised some questions for the committee.

AMNET has been shrinking over the last five years. Although we still receive a number of telephone enquiries we have very few new members – less than five a year – and each year a fairly large number of members do not renew their subscriptions – understandably they feel they are now recovered and getting on with their lives. The result of this is that there is little new blood in the organisation particularly in the committee. Most of the committee have served since the early days of AMNET. We are all getting a little long in the tooth – if not in age then in time since our own experience of AN surgery – and feel we have less to offer newly diagnosed people as the whole scenario has changed and it is difficult for us to keep up with the latest developments.

There are probably a number of reasons for this decline such as we may not be advertising ourselves enough around the hospital or people may not feel the need for a

self help group. Whatever the reasons the committee feel that there should be a debate about the future of AMNET. If we are to continue we need more people to be involved in the running of the organisation and we need to find a way of raising our profile so that people who would benefit from belonging to a self help group know we exist. We also need to look at the way we provide support for people with AN to see if it is still appropriate in the light of present management of the condition. If we decided not to continue then we would have to decide what happened to AMNET members. AMNET would probably not cease to exist totally but would become the East Anglia branch of BANA rather than an independent organisation and members could transfer their membership to BANA but this would be another factor for discussion.

In order to have this debate we have to involve all members, not just those who are able to get to meetings, as well as the health professionals who have supported the organisation. If you have any thoughts about all this please let the committee know by letter, email or telephone. Our contact details are on the back page of the newsletter. We need your opinions in order to decide what is best for AMNET and its members.



Sprowston
Norwich

Dear Editor

I am writing to you regarding two matters concerning the AMNET AGM on May 7th.

First to thank the committee for yet another AMNET AGM, which was both interesting and informative. David Baguley spoke on his special subject of tinnitus and also on the wider issues of deafness. I learn something new at each AMNET meeting! How did David Baguley make a 45 minute talk seem to last only 15 minutes!

The other topic relates to the delivery of the newsletter. Bill and I send out the AMNET News before each meeting – we were surprised to learn that two people at the AGM had not received their copy. One envelope containing more than one copy went via the local post office, the other one in our local post box. We do not know why these copies did not arrive but Alison has spare copies if you were without a copy.

Thelma Pye

AMNET Library

As some of you may be aware AMNET has a small library of books and videos which can be borrowed by members.

Two new additions to this library are:

'A Loss of Face – Facial Paralysis – a guide to self help' (3rd edition) by Diana Farragher

'Let's Face it – A True Story' by Julie Ashby

Other books and videos available for loan are:

Eva Fraser 'Facial workout' 2 copies

Rosemary McCall 'Hearing loss A guide to self help'.

Diana Farragher 'A loss of face. Facial Paralysis a guide to self help'. 2 copies.

The Migraine handbook.

BANA booklets:

Headaches, Balance, Facial Nerve, Eye Care, Overview.

Changing Faces booklet 'When facial Paralysis affects the way you look'.

Videos:

Changing Faces 'Reach Out' x 2

BANA 'Don't Panic' x 2

'Gamma Knife' (5 mins)

Do join us for our Fifth Annual Educational Conference
Jointly organised by Brain Tumour UK and the Samantha Dickson Research Trust

LIVING WITH A BRAIN TUMOUR

~Message of Hope~

A two-day event on the **18th and 19th July 2005**

At

**Jubilee Campus,
University of Nottingham**

For more information contact:

Elaine Holder, Samantha Dickson Research Trust

Century House, High Street, Hartley Wintney, Hants. RG27 8SS.

Tel: 0845 130 9733

email: elaine@sdrt.co.uk



**Brain
Tumour
UK**

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.

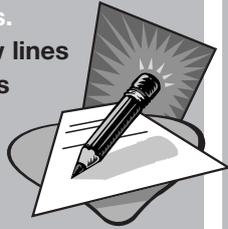
Contributions on paper and/or disc (Microsoft Word) to:-

Chris Richards

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

email: chris@richards2113.fsnet.co.uk

by: 14th October 2005



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

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

Addresses and Web sites

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

Changing Faces

(Registered Charity 1011222)

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

Switchboard Number: 0845 4500 275

Email: info@changingfaces.org.uk

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

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

RNID Tinnitus Helpline

(Registered Charity 207720)

Castle Cavendish Works,
Norton Street,
Nottingham NG7 5PN

Tel/Textphone 0115 942 1520

For further information:

Email: tinnitushelpline@binternet.com

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

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

Freephone enquiry line 0800 018 0527

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

Hearing Concern

7-11 Armstrong Road, London W3 7JL

Help Desk 0845 0744b 600

Email: info@hearingconcern.org.uk

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

AMNET Advisory Panel at Addenbrooke's Hospital

Mr David Baguley MSc MBA
Principal Audiological Scientist

Jean Hatchell

Clinical Nurse Practitioner

Mr Robert Macfarlane MD FRCS
Consultant Neurosurgeon

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

Mr N J C Sarkies MRCP FRCS
FRCOphth Consultant Ophthalmic Surgeon

The Meningioma Association UK

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

Tel: 01787 374084

Email: MeningiomaUK@aol.com

Website: www.meningiomalUK.org

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

A Basic Overview of Diagnosis and Treatment of Acoustic Neuroma

The Facial Nerve and Acoustic Neuroma

Headache after Acoustic Neuroma Surgery

Eye care after Acoustic Neuroma Surgery

Balance following Acoustic Neuroma

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

Facial Stimulators

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

BANA

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

Tel: 01623 632143 Fax: 01623 635313

Freephone: 0800 652 3143

Email: bana@ukan.freeseve.co.uk

Website: www.ukan.co.uk

FORTHCOMING MEETINGS

The next meeting will be on **Saturday 23rd July** at **Addenbrookes Hospital** in the Boardroom. Doors will open at 13.00hrs. The speaker will be **Chris Richards** who will talk about her research project '**Getting on with life' An interview-based study of the experience of undergoing and recovering from skull base surgery.** Members will be invited to discuss issues arising from the study and their own experience.

Our Christmas meeting will be held on December 3rd 2005 and the speaker is to be arranged.

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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