Newsletter of The Acoustic 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

Summer 2001
Issue18

Advances in management of the eye following acoustic neuroma surgery

A talk given by Mr N Sarkies MRCP FRVS FRCOpth, Consultant Opthalmic Surgeon, Addenbrooke's Hospital

Mr Sarkies introduced his talk by saying that he would be reviewing the problems and solutions associated with the eye following acoustic neuroma surgery. He commented that some patients are unaware that they will need the help of an opthalmic surgeon and are quite distressed to find that their eye is their main problem. To help people to understand this he described the relationship between the acoustic nerve and the facial nerve. The facial nerve supplies the face and the nerves which close the eye. This nerve is very close to the acoustic nerve in the area where the tumour occurs and is not infrequently bruised or damaged during the operation so the eye may not close properly afterwards. The nerve which supplies tears, the nervus intermedius, can also be damaged and the consequence of bruising means that the reflex production of tears may not happen for the first few weeks or months. Tears are essential to keep the surface of the eye smooth - if it becomes dry it can get infected and cause corneal damage. The eyelid produces an oily substance which smoothes out the tears also helping to keep the surface of the eye smooth, but if no tears are present this substance may become irritant.

Management of the eye in facial palsy

If the eye is not blinking and not producing enough tears it can become exposed and sore. The lower part of the eye is most affected. This is because as the eye closes it moves upwards so the upper part of the eye is generally better protected than the lower part. The lower cornea can become very sore and often the lower lid becomes slack. A small operation which shortens the lid can be carried out fairly soon after surgery to alleviate this and it has no ill effects if the nerve recovers.

There are a number of things which will help prevent damage to the eye by increasing lubrication or protecting the eye.
The strategy known as 'think blink' is encouraging people to think about blinking their affected eye as often as possible. Normally the eye blinks about seven times a minute and this helps with the production of tears.

The use of ointments can be very beneficial. They last longer than drops but do smear the vision. Ointment can be used 5 -6 times a day and particularly at night. Drops give better vision but need to be used more frequently.
It is best to avoid products with a preservative as most people will develop an allergy to the preservatives eventually.
The other thing which is important is that people need access to an eye clinic, as, if they do have any problems they need to get help quickly.

A very small dose of **botulinum toxin** can be injected into the upper eyelid which paralyses the muscle and keeps the lid closed so the cornea of the eye is protected. This lasts about 3 - 4 months but can cause double vision.

Tarsorrhophy is the stitching of the eye together leaving a smaller area exposed. This is very effective in protecting the eye but is disliked by patients because it restricts vision and may be uncomfortable. It may be done as a temporary or semi-permenant measure.

Gold weights can be used to give the eyelid extra weight which helps it to close while not preventing it being opened. This may be inserted if there is no sign of nerve recovery after 6-9 months.

Mr Sarkies then answered a number of question from the floor.

He was asked about why as the nerve recovers patients experience **'crocodile tears'** when they eat. He suggested that there is a speculative theory that the nerve supplying tears and the nerve supplying saliva are misfiring so that tears are produced at the time of salivating. It has been suggested that injecting the lachrymal gland with botulinum toxin can stop 'crocodile tears'.

Further discussion about tears elicited that 'emotional' tears are produced through a different mechanism from normal tears and have a different constitution, being more watery. A fairly new

Next meeting

A special AGM to celebrate 5 years of AMNET will be held on Saturday **June 2nd 2001** at Addenbrooke's Hospital in the Boardroom from 10.30 - 16.00 hrs. We have invited **Diana Farragher MSc, Grad Dip Phys, Dip TP, FCSP**, a physiotherapist with a particular interest in facial problems and author of 'Loss of Face' for the morning. She will speak on **'Facial Rehabilitation - a must for all patients with Cranial Nerve 7 Damage'** There will be speakers on Complementary Therapies in the afternoon. Lunch will be provided

treatment for 'dry eye' which helps to preserve the tears the eye is producing is a punctal stop which is placed in the duct which drains tears to the lachrymal sac and stops them draining away thereby allowing more moisture to stay in the eye.

Mr Sarkies was asked about problems with eyes drying out when flying and he suggested this is because of the air conditioning on planes and the solution would be to use ointment more often when flying. Another problem was hill-walking and it was suggested that protective shields to add to glasses can be obtained from opticians.

The problem of sticky eyes in the morning was also a result of lack of tears allowing the substance produced by the eyelids to accumulate and would be alleviated by the use of ointment.

Mr Sarkies again emphasised the importance of ointment and drops, particularly those without preservative. He said that work is being done towards finding substances closer to tears, but as tears have a very complex composition the solution may still be some way in the future.

We would like to thank Mr Sarkies for his interesting talk and willingness to answer our questions.

postbag

I reproduce some parts of the following letter sent to Alison

Hellesdon, Norwich

Thank you so much for the literature you sent me. I found it very informative and in many ways reassuring. I wish I had known of your organisation before my operation. My own GP has been of no "use" to me either before or after my operation.

I look forward to receiving the next newsletter to stop me feeling so 'alone' in all this. I felt I was unique with the 'dropped face syndrome' until reading your newsletters and it seems quite normal.

A tip you might like to pass on to your readers was that I found eating quite messy until I used a free standing hand mirror.

Thanking you once again

Jennifer Wright

This next letter was sent to Alison recounting a member's experiences in deciding on which treatment to have, gamma knife treatment and her subsequent recovery.

Diss, Norfolk

The first time I heard of stereotactic radiosurgery was when I read Martin Kemp's autobiography - by coincidence that was a month before my diagnosis. So when I was first told about my AN, my immediate thoughts were that a non invasive treatment existed and I should find out about this. From the internet I gleaned much information and I am very grateful I was able to do this. I believe I have gained a great deal by being able to go to a specialist with certain prior knowledge. It is hard to take in facts delivered to you for the first time in a 20-30 minute consultation and make decisions on that basis.

I have an appointment for the next scan at Addenbrookes and a follow-up appointment with Mr Moffat. The Health Authority won't pay for follow-up with Mr Lindquist at the Cromwell, but I understand he hopes that the scans will be sent to him for review.

I am back at work now and carrying on much as normal. I think the stress and worry of the year since I was diagnosed took it's toll eventually and I did feel very exhausted for a week or so after Christmas. I did need a couple of weeks at home to recover my equilibrium, but after that I felt better getting back into a working routine.

Apart from headaches when I get tired, (my working day involves looking at a computer screen most of the time, so I cannot attribute this to AN or the treatment for sure). I am fine and live at the same level as before. I still have tinnitus and the hearing problem, but all very manageable.

I am grateful for the help I received from people I have known about only through BANA and I would be pleased to talk to anyone about my experience which is, of course, ongoing.

Best wishes

Carole Walden

This last letter is a plea from a member in Hong Kong. Maybe someone out there can help.

Hong Kong

I had my AN operation at Addenbrooke's nearly 5 years ago and have adjusted really well to all the post operative problems. My major concern was the usual dry eye and I have experimented with a wide variety of drops. Three years ago I was recommended to try TEARS NATURALE II, made by Alcon: it has been a miracle. I am unable to use the original Tears Naturale. My problem is that I seem unable to get the new version in England. It is readily available in all the large chemists in Hong Kong, but no-one in the UK seems to have heard of it. I will soon be returning to England (Kent) and am really worried about not being able to source it. I dread the thought of going back to the discomfort I used to have.

I should be most grateful if AMNET could do some research for me - or point me in the right direction. Your readers may well find this product a solution to their dry-eye problems, as I have.

Yours sincerely

Ruth Collins

Editorial

Dear All

Welcome to another edition of AMNET News. I hope you will enjoy what we have for you this time.

There are a couple of things I would like to highlight. Ray has told me that a number of people do not know if they are entitled to any benefits or allowances if they are unable to work or need help following surgery. The article on page 4 offers a summary of some of the allowances and benefits which are available. If, after reading the article you think you might qualify for some help then contact your social security office who should be able to help you make a claim.

There is also some further information on the after effects of radiosurgery which I have obtained from a recent medical journal plus a letter from a member who did her own research in order to decide which treatment to have. Please write with your experiences of making the decision or of having radiosurgery as all information is helpful to others who have to make the decision.

The most important item this time is the reminder for the AGM. I hope you will all know about this and have responded to our invitation before you receive this newsletter. (Unfortunately I am on a very tight schedule this time so I hope this reaches you before the meeting.) However we will be pleased to receive any volunteers or nominations for committee members right up to the meeting. The present committee are willing to continue but new blood is always necessary and welcome, so if you think you can help in any way, however small, please contact one of the committee members.

Finally don't forget that this is your newsletter and it relies on contributions from the readers to keep it interesting. Please write to me about your experiences, views or concerns and I will pass them on to the other members. It can be any length - nothing is too short!

Best wishes

Chris.

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.

AMNET

is 5 years old and we would like to invite you to help us celebrate this occasion.

We are holding our AGM on Saturday 2nd June 2001 in the Boardroom at Addenbrooke's Hospital

The programme for the day is:-

10.30	**Coffee**
11.00	Diana Farragher MSc Grad Dip Phys. Dip TP. FCSP
12.30	AGM Agenda Apologies Minutes Matters Arising Chairman's Report Treasurer's Report Election of Officers
13.00	Lunch
14.00 - 16.00	Complementary Therapies

We look forward to seeing you.

Treasurers Report April 2001

The books have been audited and the account is currently looking very healthy, we have roughly £4,000. We are seeking ideas from members on how we can usefully spend some of this money, so if anybody has any ideas please contact me and I'll put them forward to the committee.

I've also been investigating how we can claim the tax back from the Inland Revenue, on everybody's subscriptions and donations. This mainly seems to involve trawling through reams of paperwork. I will be sending a declaration form to every member when your subscription is due for renewal. If you could please fill the form in, sign it and return it with your subscription it would be appreciated. This will allow us to claim the tax back on this, and all your future subscriptions or donations.

See you all at the AGM in June. Bye for now.

Jo.

Are you entitled to any financial help?

Ray has been receiving a number of enquiries about benefits which may be available to people who are sick or disabled. I have put together this article from information published by social security and the benefits agency.

If you are unable to work or need help looking after yourself or getting around there are a number of benefits and tax credits which you may be able to claim. In this article I will highlight some of the benefits for which members may be eligible. To obtain any of these benefits you need to make a claim through the new ONE service in your locality or your local social security office.

Statutory Sick Pay (SSP)

Statutory Sick pay is paid by your employer for up to 28 weeks:-

- if you have been sick for at least 4 days in a row
- you were employed when you became sick
- you are earning enough on average for it to be relevant for National Insurance purposes

Incapacity Benefit

Incapacity Benefit is paid if SSP has ended or you cannot get SSP. It is not paid if you were over state pension age when you became sick. You need to have paid National Insurance contributions. It is paid at three different rates:-

- **Short-term Incapacity Benefit** at the lower rate which is paid if you do not get SSP and have been sick for at least 4 days.
- **Short-term Incapacity Benefit** at the higher rate which is paid if you have been sick for more than 28 weeks and less than 52 weeks.
- **Long-term Incapacity Benefit** which is paid if you have been sick for over 52 weeks.

To claim this benefit you will usually need to go for an interview with a ONE personal advisor. Extra money may be available depending on factors such as age, when you became sick and whether you have children or other dependants.

Disability Living Allowance (DLA)

You can make a claim for DLA:-

- if you need help looking after yourself
- you are under 65 years of age
- you have difficulty walking or need help getting around.

You must have needed help for 3 months and be likely to need it for at least another 6 months.
You can get DLA even if no-one is actually giving you the care you need and it is not affected by savings or any other income

Attendance Allowance

You can make a claim for attendance allowance:-

- if you need help looking after yourself
- if you become ill or disabled on or after your 65th birthday.

It is paid at different rates depending on whether you need care during the day, night or both. In order to claim you must have needed help for at least 6 months. You may receive AA even if no-one is actually giving you the care you need but you may not get AA if you are in hospital or residential care. AA is not affected by savings or usually by any other money you may have coming in.

Disabled Person's Tax Credit

You may be able to claim Disabled Person's Tax Credit:-

- if you are working on average 16 hours or more but are restricted in the type of work or number of hours you can do because of illness or disability.
- if you are receiving short-term incapacity benefit paid at the higher rate or long-term incapacity benefit or receiving a disability premium on Income Support, Jobseekers Allowance, Housing Benefit or Council Tax Benefit. Receiving Disability Living Allowance or Attendance Allowance may also allow you to claim.

It is not paid if you have savings over £16000 and savings over £3000 will affect how much you can get.

Invalid Care Allowance

Invalid Care Allowance is paid to full time carers who are:-

- aged between 16 and 65
- spending at least 35 hours a week looking after someone who is receiving or waiting to hear about one of these other benefits :- Attendance Allowance, Disability Allowance at middle or higher level of personal care.

To claim you will need to go to a meeting with a ONE personal advisor.
You cannot get ICA if you are in full-time education or earning above a certain amount. If this is paid it may increase or decrease other benefits you receive and it may decrease some benefits received by the person you look after.

Income Support

Income support is paid to people on a low income. If you have savings of over £8000 that usually means you cannot get Income Support. To claim you need to be:-

- aged 16 or over
- on a low income
- not working or working on average less than 16 hours a week and your partner works less than 24 hours a week.

You have to claim through your ONE centre and savings can affect the amount you receive although you may be able to get extra money if you are buying your own house or have a dependant family.

Housing Benefit and Council Tax Benefit

This is paid by local council to people who are on a low income. You do not have to be receiving any other benefits but you do have to claim through your ONE centre. You can get leaflets on 'Help with your rent' and 'Help with your council tax' which will give you more information. Help may also be available for health costs such as prescriptions, dental care and sight tests.

The information for this article is a brief summary and was obtained from a booklet called 'Sick or Disabled' produced by DSS Communications. Further information is available from your ONE centre or social security office which you can find in the phone book under Benefits Agency

The DSS website address is **http://www.dss.gov.uk**
The ONE website address is http//www.one.gov.uk
A confidential telephone service is available for people with disabilities and their carers. Ring the **Benefit Enquiry Line (BEL)** on **0800 88 22 00**. People with speech or hearing problems using a textphone can dial **0800 24 33 55**.

Update on Radiosurgery

As a follow-up to my article about microsurgery and radiosurgery in a recent edition of the newsletter I would like to report on two articles which appeared in the Journal of Neurosurgery January 2001. They both present results from a series of patients receiving radiosurgery.

Results of acoustic neuroma radiosurgery: an analysis of 5 years experience using current methods
John C Flinckinger, Douglas Kondziolka, Ajay Niranjan and L D Lunsford

This article is produced by a team from Pittsburgh, Pensylvania who present results from their first 5 years of using gamma knife radiosurgery for patients with acoustic neuroma. They treated a total of 190 patients between 1992 and 1997 and assessed tumour regrowth, hearing and facial weakness and numbness in a follow-up period averaging 30 months. From their results three patients underwent surgical resection of the tumour after treatment and another 10 patients did show a temporary or permanent increase in the size of the tumour, although these then remained the same or subsequently decreased. 4 patients showed some decrease in sensation of their trigeminal nerve and facial weakness or numbness occurred in a total of 4 patients. They found that there was no incidence of facial weakness exhibited in patients who had been treated with the lower radiation doses used later in the series. Hearing levels were preserved in 103 out of 133 assessable patients and this also seemed to relate to lower radiation dose. The overall conclusion of the paper was that 'Acoustic neuroma radiosurgery, is associated with a high rate of tumour-growth control, high rates of hearing preservation and minimal risks of causing facial and trigeminal morbidity.

Linear accelerator radiosurgery for vestibular schwannoma
R Spiegelmann, Z Lidar, J Gofman, D Alezra, M Hadani and R Pfeffer

This article was produced by a group from Tel Hashomer, Israel and reports results from a series of 44 patients with acoustic neuroma treated with linear accelerator (LINAC) between 1993 and 1997. 10 of these patients had undergone previous surgery to remove part of the tumour. They give a definition of stereotactic radiosurgery as any technique that delivers a single dose of ionising radiation from an external source to a stereotactically defined target, ensuring a steep radiation falloff beyond the limits of the lesion. This means that the radiation is directed only at the tumour and aims to touch as little of the surrounding tissue as possible. The average follow-up period for these patients was 32 months (Range 12 - 60 months). Early tumour enlargement was observed in 11 patients in the first year and 8 of these developed a facial neuropathy. Tumour volume reductions were seen in 75% of the patients 12 - 36 months after radiosurgery. At the end of the follow up period 10 tumours were shown to have preserved their original volumes and in summary they suggest that 98% of tumours in this series are currently controlled. They state a hearing preservation rate of 71% and say that new facial neuropathy developed in 24% of the patients who did not have a total loss of function before radiosurgery. This reduced to 8% at the time of writing the article. They also report that 2 patients showed improvement in facial nerve function after treatment. This group also suggest a link between lower doses of radiation and improved results in hearing preservation and facial nerve neuropathy. They suggest that 'Currently and based on the comparative results presented herein for tumour control, facial nerve function and hearing preservation, we believe that radiosurgery can be offered as the primary treatment modality for acoustic neuromas of suitable size, regardless of the patients medical status'. They suggest that long term follow-up review of patient outcome in gamma knife radiosurgery found a tumour-growth control rate (shrinkage or unchanged tumour size) of 95%. Radiosurgery aims at the biological elimination of the tumour rather than the physical elimination. Their final argument is that tumours compressing the brainstem or larger than 3cm are unsuitable for radiosurgery. They also suggest that if a centre with good track results with microsurgery is available this should be offered as the treatment of choice to a young patient because there is still concern about the theoretical long-term complications of radiation therapy for benign tumours.

AMNET Library - More Findings from the AMNET Members' Survey 2000

Treatment & Medication: most troublesome post-operative AN problems

In the survey, members were asked: ***"Have you found anything which helps you to cope with it*** *(i.e. the three most troublesome problems)?" We had 560 responses to this question.*

Over half of you (58%) did **not** find anything that helps. Of the 42% of you who did find something, over a third (38%) find medication helps, almost a third (32%) benefit from medical treatment while over a third (39%) find a variety of other measures are helpful. Of these about 10% said that a combination of measures are effective.

There is considerable variation in the effectiveness of these measures depending upon the specific post-operative problem. For example, almost everyone finds some way of helping dry eyes and headaches; whereas almost no one seems to have discovered any answer to coping with tears while eating, apart from using a tissue.

Of the most troublesome problems many of the measures you find helpful are as might be expected: almost everyone troubled with dry eyes use drops or ointment and with headaches taking medication usually helped. In addition, in both these cases quite a number (20%) find medical treatment helpful.

You have come up with a wide variety of suggestions that have been helpful to you. These are summaries of your suggestions:

A. General

1. *Be positive (frequent response).*
2. *Live life to the full: do things you enjoy doing.*

B. Hearing

1. *Let people know you have difficulty hearing.*
2. *Where appropriate on 'social occasions', place yourself in a corner.*
3. *Try lip reading and have a good sense of humour.*
4. *Put your husband on your deaf side!*
5. *CROS aids can help. (A few did not find them so.)*
6. *If you wear glasses all the time, have a hearing aid attached to your glasses on your good side and a microphone on the other side (CROS).*
7. *Put a plug in your AN ear if you are affected by loud noises.*

C. Balance/dizziness

1. *Avoid stress and pressure.*
2. *Get up slowly.*
3. *Don't drink alcohol!*
4. *Visit a gym.*
5. *Play golf.*
6. *Go walking and take exercise - don't rush, but concentrate and focus upon the horizon.*
7. *If cycling, have a rear-view mirror.*
8. *Have night lights around the house when dark (plug in ones from ASDA).*
9. *Take Cinnarizine; i.e. for travel sickness.*

D. Tinnitus

1. *Just ignore it.*
2. *Seek advice from specialist consultant.*
3. *If caused by loud noise, put plug in AN ear.*
4. *Keep busy in the garden.*

E. Dry eyes

1. *Try a variety of drops and ointments until you find what suits you.*
2. *Use wrap-around sun-glasses or safety glasses when cycling or hill-walking.*
3. *Use tinted glasses.*
4. *Taping at night can help.*
5. *If sore, bathe in weak baby shampoo then put in drops.*
6. *'"Chloramphenicol" got rid of my infection'.*
7. *"Simple" eye ointment lessens blurring.*
8. *'Insertion of silicon tear duct plugs have overcome my problem'.*

F. Facial movement & appearance

1. *Try not to get too tired.*
2. *Don't expose your face to cold winds - use scarves and hats.*
3. *Chewing gum helps (dry eyes too).*
4. *Use facial stimulator with physiotherapist and bio-feedback programme.*
5. *Facial sling helped a bit.*
6. *"Tegretol" helps.*
7. *'I was worse after taking aspirin'.*
8. *"Face lift" by plastic surgeon has helped.*

G. Tears when eating

1. *Take smaller mouthfuls.*
2. *Avoid spicy, salty or citrus flavoured food and food that takes a lot of chewing.*
3. *Wear waterproof mascara (ladies only!)*

H. Difficulty chewing/swallowing

1. *Take small mouthfuls.*
2. *Eat moist food and have a glass of water available.*
3. *Use a straw.*
4. *If mouth is dry, take "Glandosane" (synthetic saliva).*

I. Taste (saline)

1. *Don't cook with salt.*
2. *Suck strong XXX mints or fruit drops.*
3. *Chew gum.*
4. *"Drink plenty of water (or wine!)"*

J. Speech difficulties

1. *Try taking time before speaking.*
2. *Hold side of mouth (difficulty with 'p's and 'b's).*
3. *"Insist on seeing a speech therapist."*

K. Headaches

1. *Wear a soft neck collar at night.*
2. *Try a variety of painkillers.*
3. *Try "Diclofenac" (anti-inflammatory drug known as Voltarol) or "Amitriptyline or "Zolmitritan".*
4. *"Use "MI-GON" roll-on of essential oils: very pleasant and helpful"*
5. *Try acupuncture.*
6. *See cranial osteopath.*
7. *Visit pain clinic.*
8. *Nerve end denervation by injection may help.*
9. *Botulinum injections (at 3 monthly intervals) may also help.*

L. Other pain

1. *'Hold hand over corner of mouth and apply pressure'.*
2. *'Removal of hard wax in ear got rid of my facial pain'.*
3. *Visit pain clinic*

M. Tiredness

1. *Do something interesting.*
2. *Do things at a slower pace.*
3. *Take "Amitriptyline" or anti-depressant.*

N. Loss of sleep

1. *Take hot milk drink last thing at night.*
2. *Take sleeping tablets such as "Valerian" (a herbal sleeping aid).*

O. Lack of concentration

1. *Join relaxation class.*
2. *Embark on a course of study or occupational therapy.*
3. *Take "Risperidone" tablets.*

P. Loss of memory

1. *Follow a study course*
2. *Take Gingo Biloba*

Q. Depression

1. *Compare yourself with others worse than yourself.*
2. *Take "Seraxot, Amitriptyline (low dose), Dothiepin or Parnate'.*

I hope that you find some of these suggestions are helpful. If you would like more details do contact me. However, do contact your GP or specialist consultant before trying any of the medications or treatments.

Ray Maw

If anyone has any other suggestions or comments on this please let me know for the next newsletter **Ed**

The Nye Bevan Awards

The Nye Bevan awards are awarded to individuals and teams within the NHS and celebrate the best examples of good practice. Brian Bagnall was on the panel of patients and carers who chose the winners of these awards and wrote about it in an earlier newsletter. This is an update on the winners who were presented with their awards in a ceremony at the London Arena last July.

Brian writes:
Our regional winner was from Norfolk and Norwich Hospital was for work on deep vein thrombosis. It was also the runner up for the overall National Award. The North West Region won the overall award for work on chronic refractory angina.

In the section on lifetime achievement awards we found it hard to judge between two entries and Alan Milburn allowed us to award tied winners. These were Jenni Thomas and team at South Buckinghamshire NHS Trust for work on neonatal bereavement facilities and Professor Jillian Mann for work on cancer in young children at Birmingham Children's Hospital. It was very nice to share a trip to the Dome with the prize winners after the presentation.

Sadly there were no prize winners from Addenbrooke's. Work at Manchester on acoustic neuromas including double sites was amongst the 200 entries that were not selected for the 6 most outstanding..

Fundraising

We have tried to raise funds for AMNET by seeking donations from business organisations, but unfortunately they are unwilling or unable to help, being frequently inundated with similar requests, so I think it is now our responsibility to raise our own funds.

There are a lot of simple ways to do this, especially holding a coffee morning or tea party in your own home. You can invite friends and neighbours, telling them the purpose of the occasion. Arrange to have a few leaflets or other information about AMNET and acoustic neuroma and meningioma on display and you will soon find that you have raised £10 or £15 with very little effort (and a cake stall is always popular!). If you are more ambitious, a sponsored event such as a swim, tennis tournament or run will often bring in quite as tidy sum. Many areas organise mini-marathons etc for people to join in and get sponsorship for their pet charity. I am still trying to complete my swim: unfortunately I have not been able to do much recently, but I hope to start again soon.

We have in the past, received some very generous donations as a result of events arranged by members and supporters and we all value the help and encouragement of Alison and the committee. So, please, if you wish the good work to continue and future patients and their supporters to benefit as we have done, put on your thinking caps and RAISE SOME MONEY!!!!

Eleanor Monk

Congratulations

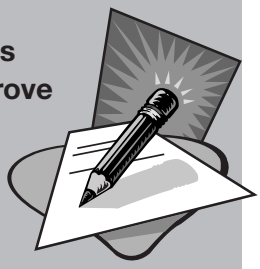
We would like to congratulate Brian Bagnall on being elected mayor of Bury St Edmunds. We hope he enjoys his time in office and that his success will spur others on to even greater things after surgery for AN!

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

by

14th July 2001

Surfing the Net?

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

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

Also 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

With thanks to BANA for the information!
Email: bana@btclick.com
Website: http://www.ukan.co.uk/bana/

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.changing faces.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)
(Registered Charity 1011145)
Web site: http://www.tinnitus.org.uk/
Email:bta@tinnitus.org.uk
The BTA is a charitable organisation which supports a network of self-help groups and contacts. The association provides information and advice to help people to come to terms with tinnitus and supplies helpful retraining audio casette tapes and details of relaxation cassettes. For an annual subscription members receive "Quiet", the association's quarterly journal.
Contact: BTA 4th floor, White Building, Fitzalan Square, Sheffield S1 2AZ

AMNET Advisory Panel at Addenbrooke's Hospital

Mr David Baguley MSc MBA
Principal Audiological Scientist

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

Sue Woodford RN
Staff Nurse Clinic 10

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.

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

As many of you are aware we have an extensive library of books, booklets, articles, videos and tapes which members can borrow.

If you would like to know more please contact Ray or Alison.

FORTHCOMING MEETINGS

June meeting

A special AGM to celebrate 5 years of AMNET will be held on **Saturday June 2nd 2001** at Addenbrooke's Hospital in the Boardroom from 10.30 - 16.00 hrs. We have invited **Diana Farragher MSc, Grad Dip Phys, Dip TP, FCSP**, a physiotherapist with a particular interest in facial problems and author of 'Loss of Face' for the morning. She will speak on '**Facial Rehabilitation - a must for all patients with Cranial Nerve 7 Damage**' There will be speakers on Complementary Therapies in the afternoon. Lunch will be provided.

The meeting in September will be held on **Saturday 22nd September** at 13.00hrs at Addenbrooke's Hospital and the speaker will be **Mr Robert MacFarlane MD FRCS Consultant Neurosurgeon**

Facial Stimulators

AMNET has some Facial Trophic Stimulators which are available to members for short term loan. There is a charge of £20 at present which includes maintenance and postage. If you would like to know more please contact:**Margaret Allcock on 01493 700256**

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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