

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

Winter 2000
Issue 16



*Merry Christmas and a Happy New Year
to all our Readers*



Editorial

Dear All
Welcome to our Christmas edition and may I be one of the first to wish you the compliments of the coming season and all the best for the new year.
Initially I was a little worried that I would be short of material for this newsletter because, as many of you will know, our autumn meeting had to be cancelled because of the fuel crisis so I did not have a leading article. Instead I have put together information about trophic stimulators and we also have an article from someone who has used one. If any more of you would like to share your experiences of using a trophic stimulator please write and let me know. It was also good to get some letters in response to articles in the last newsletter - again keep them coming! One of the purposes of this newsletter is to open up debates about important issues such as alternative treatments and availability of information. So when you are recovering from all that turkey and Christmas Pud please take a few minutes to drop me a line - it needn't be very long- but it all helps to keep the newsletter interesting.

Chris.

Chris

Approaches to Facial Paralysis

Many patients suffer a degree of facial paralysis following surgery for the removal of an acoustic neuroma or meningioma. This can be very distressing and may result in difficulties with closing the eye on that side and with eating, as well as the associated change in appearance and therefore self-image. For many patients the paralysis will improve considerably over the first few weeks following surgery when bruising and trauma, resulting from the operation, resolve. However, often a degree of weakness remains and although there will be some gradual improvement over months or even years many patients feel they would like to be doing something more positive towards this improvement. In some recent newsletters we have reported on surgery which can improve the nerve supply to the facial muscles, but in this article I will discuss the use of Trophic Electric Stimulation. This treatment can be used on a regular basis to improve blood supply to the facial muscles and so enhance the action of nerve fibres as they re-grow. The word 'trophic' is about good health and systems which thrive. Trophic electrical stimulation copies the underlying signals which the nerve gives to the muscle to keep it in good health. The repeated signalling is the impetus for the muscle to rebuild itself and it will do so according to the exact specifications.

The person who has done most to promote this treatment for facial paralysis is Diana Farragher, a physiotherapist based in Manchester. Her original work in the mid eighties was with people who had suffered from a condition called Bell's Palsy which is paralysis of the facial nerve which may be the result of an infection. She designed a stimulator which would copy the signals produced by healthy facial nerves and showed that with the support of a chartered physiotherapist and regular use of the machine over a period of more than 4 months excellent results have been seen.

Diana has written an article for the last issue of BANA Headlines in which she describes the process as one in which *'the nerve needs to work to grow back. As it grows back in a piecemeal type of way, the owner of the face constantly needs to make adjustments to restore balance. So often, when the face looks better from*

the outside, it feels worse on the inside. The person on the inside needs to learn to work the face again; it is stiff, it twitches and it refused to obey signals. The nerve needs to 'grow up' and behave itself. The techniques I now use for this vary from sEMG, electrical readings of nerve activity, to biofeedback - small units used at home to exercise the face which save looking in a mirror. These units are rather cumbersome at present, but we are working on that.

.....The skill of a physiotherapist is required to retrain normal movement patterns; if left to it's own devices synkinesis or mass patterns are as far as recovery will go. BANA has a list of physiotherapist who I have trained in my techniques, 61 are NHS based.... If there is no-one near you, then you can ask the physio to contact me re training'.

Diana and her daughter Jenny have also reported results of a questionnaire sent to people who have used their machines. They have been completed before, at six months and at twelve months follow-up from starting to use the machine. Although the sample is small (33 people) they have shown that 94% people reported that overall movement of the affected side of the face had improved or stayed the same at follow-up, 69% reporting improvement, some by more than 25%. The length of time since onset or the initial severity did not seem to be a barrier to improvement. People also felt better about their face at follow-up. Practical problems such as eating and drinking showed improvement in a high percentage of the group and dryness or tearing of the eye also improved in 67% after 12 months.

Next meeting

The next meeting will be our Christmas meeting on Saturday 9th December. The doors will open at 12.00 and our speaker will be: Mr David Baguley MSc MBA Principal Audiological Scientist

Don't forget to bring some food to share.

So overall it does seem that using a trophic stimulator can be helpful in cases of facial paralysis. I think it needs to be noted that success is related to a certain amount of dedication to use of the stimulator and carrying out facial exercises by the participant. I have an article by one of our members who has used a stimulator in the newsletter, and I hope this will give you a personal viewpoint.

To obtain further advice for members who are thinking of trying a stimulator, and we do have a few which we are able to loan to members, I wrote to Diana with some specific questions which she has answered and I have printed part of her letter below.

'Before embarking on stimulation it is worth establishing the presence of the nerve. The surgeon may be able to tell you if the nerve was cut or alternatively it can be established through testing ie sEMG (electromyography). If the nerve is there stimulation will help, if not it may be worth considering further surgery.'

Your members can expect to treat for 1 hour daily for at least 4 months, although generally it would be a year. This isn't as arduous as it sounds since once the machine is on you can carry on with whatever you were doing - even sleep since it turns itself off. As to likely results Basically people can realistically expect an improvement in lip seal ie better eating, no more drinking through straws or slurring your words. They can expect more movement as well as better symmetry at rest. They won't get a 'perfect face' - they don't exist.

As far as physiotherapy goes there are several options. I have lectured extensively and there are physiotherapists trained in this area.....Secondly there are manuals provided with the machines for physiotherapists usage and they can always call the help line for guidance.

The other option if course is to visit my clinic on a self referral basis. Although it is a private clinic I only see each patient 3 times a year and find that many people manage to travel to see me. I am opening a new centre and will offer sEMG testing, Biofeedback training (ie relearning to use your face) and make up lessons (to hide problem areas, highlight symmetry etc.)'

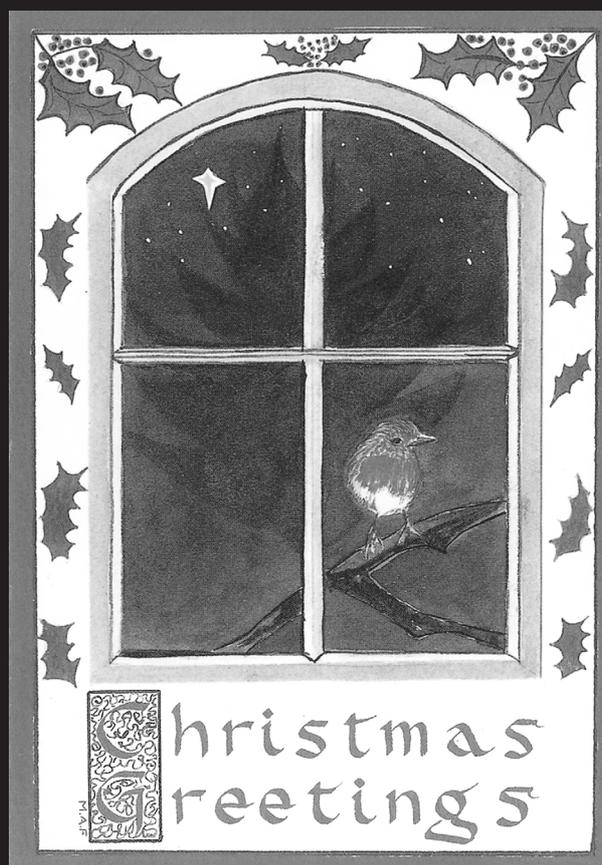
I hope you have found the information in this article helpful. I offer many thanks to Diana Farragher who provided the information on which I based the article. If you want to know more from her she can be contacted at;

Diana Farragher MSc, Grad Dip Phys, Dip TP, FCSP
3 The Meade **Tel 0161 718 8620**
Chorltonville **Email: dfarragher@ic24.net**
Manchester
M21 8FA

Facial Stimulators

AMNET has a 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 01473 700256

BANA Christmas Card



Please help to raise the Association's profile and support BANA by ordering your BANA charity Christmas cards by completing the order form below. **ALL profits go to BANA UK!!!** Cards are in packs of 4 with suitable envelopes, costing £1.80/pack, together with a charge for post and packing of 70p to cover up to 5 packs of 4 cards, or £1.50 for orders of more than 5 packs. Thank you for your support!

Number of packs (4 cards per pack)	Total
Please send me packs, at £1.80 per pack	@£1.80/pack
Add Post & Packing (70p for up to 5 packs, £1.50 for more than 5 packs)	70p or £1.50
Total order - please make your cheque payable to "BANA"	£

Signed: Date:

Please enter your name and address (including your postcode) in block capitals below:-

Post your completed order form and cheque to me, and I will despatch your order as quickly as possible:-

Name:	Mrs Anne Frost
Address:	Quill House, Main Street Aberlady, East Lothian
Postcode:	EH32 0RB
Telephone:	01875 870405



AMNET Member's Survey 2000 Preliminary Findings

Yet again you have made a wonderful response - 97.5%

Of the missing respondents, one has disappeared east, one west and one entirely. One lady, who was so excited about the prospect of cloning more Mr. Moffats, returned the questionnaire but forgot to fill it in!

I also sent out questionnaires to a random sample of 33 past members and received just over 60% back.

Overall we now have data from exactly 200 acoustic neuroma members - a useful sample - and also some from our meningioma and glomus members.

Thank you all very much for your support.

As expected, the "perceived levels of impact upon the quality of life" are similar to the previous surveys; however, there are a number of differences. The 2000 survey includes additional problems: hearing loss, difficulty closing eyelid, facial problems, speech difficulties, difficulty sleeping, loss

of concentration and memory loss giving a total of 29 listed problems.

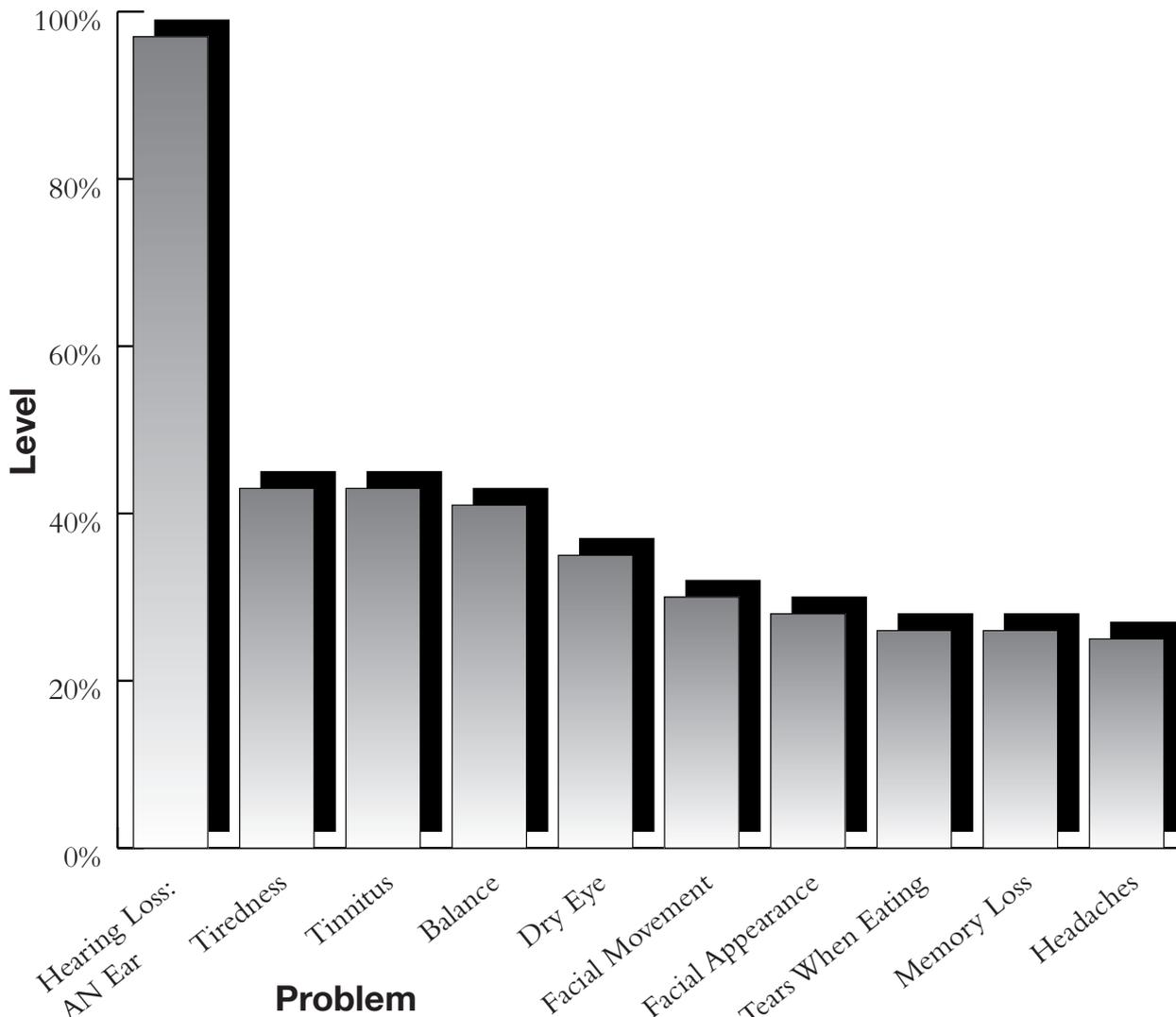
The "levels of impact" of these problems are measured as a percentage of the maximum possible impact, in other words, if everyone were suffering "very much" from a particular problem. In the case of members who have had an acoustic neuroma operation, the perceived impact of hearing loss in the AN ear is 97%. The impact of all other problems is below 50%; with tiredness and tinnitus being the highest at 43% and balance at 41%. Other "common" problems (over 25%) are dry eye (35%), loss of facial movement (30%), facial appearance (29%), tears when eating, headaches and memory loss all at 26%.

One of the most significant differences from the 1998 survey is "tears when eating". A possible explanation for the apparent increase may be due to the larger proportion of members who had their operation some time ago.

I now propose to do a "time series analysis" using the 1998 and 1999 survey data to find out recovery rates which may provide some useful information and also perhaps explain some of the differences between the survey results.

I hope to be able to report more findings in AMNET News as the analysis progresses.

Ray Maw



The Power of Thought (and a trophic stimulator)

This article comes from Brian Lock in response to my request for a personal account of using a trophic stimulator. I think Brian's account shows that he is a very single minded and determined person and this plus a positive attitude has obviously contributed to his recovery. I hope you enjoy his account and it may prompt some more of you to let us know how you have helped yourself to recovery. Ed

Being one of the very few, as I understand it, to have one's facial nerve cut during the removal of an acoustic neuroma, I started my recovery at what I considered a distinct disadvantage to most other acoustic neuroma patients.

Fortunately, however, over the last two years since my operation, my facial nerve appears to have now virtually re-grown, although at times I feel that there is still along way to go, particularly when the muscles get tired and the mouth droops slightly. But then it perks back up again.

Progression had been slow, but in an effort to give encouragement to other acoustic neuroma patients, whose face recovery is possibly a little delayed or maybe prolonged, I feel I would like to share my story of the practical efforts and mental application I pursued in my attempts to get some form of restoration in the nerve.

I remember quite vividly the first discussion with Mr Hardy following my surgery, when, through the postoperative stupor of the anaesthetic, he sat on my bed and explained that he had had to cut the facial nerve to get the tumour away in one piece. Mr Hardy felt that as the tumour had encompassed the facial nerve it would be far better to take the tumour away whole in its sac rather than in pieces with the possibility of leaving a small piece behind to regenerate. I would not have wanted any other decision.

He explained that he had re-sown the nerve deep in my head, but could only do so on one side, as the other side was up against the spinal column. (How do they do it?) I was told that whilst nerves do regenerate and grow, the chances of them doing so are less than evens, and that mine would not necessarily re-grow. Apparently the scar tissue forming across the end of the cut nerve sometimes prevents the nerve fibres from breaking through.

Whilst immediately post-operative, I did not fully take in the implication of what I had been told, it did cause me quite considerable consternation, when after about 48 hours, I looked in the mirror. I remember saying to my wife and son, "What a B..... mess", a comment which was met with the heart-warming response from my son, who said, "It's a good job you're already married Dad."

It was around this time, I remember making a promise to myself that as I considered the mind to be a very powerful

instrument, I would utilise the power to regain my full health as soon as possible. I set about 'willing' the cut nerve to burst through the scar tissue and start re-growing. I knew in my heart, at that early stage that I would get the nerve to re-grow again, and happily for me those desires have all but come to fruition.

I was up and walking almost as soon as the anaesthetic had worn off and out of hospital on the sixth day. I was far from well and in the weeks following, for some part of each day, I felt that I was not within my body. My wife and I used to go for long walks and I would often say that I was floating above and outside my mind. It was a strange light-headed feeling of my mind not being where it should be inside my head. That feeling would last for anything from 10 minutes to a couple of hours but as the days progressed they became less frequent and disappeared altogether after about six weeks.

Whenever I had one of these 'out of body' experiences I would literally force my mind back into my body, and I used this concept to force my nerve to re-grow. Whether it was my will-power that did it or a normal bodily reaction to the predicament my body was in, I do not know, but it made me feel good and gave me a lot of encouragement as time went on.

Every single day, on numerous occasions during each day, I would get behind the nerve, wherever I thought it was on its re-growth trail and mentally drag it along its course. A nerve is supposed to grow 1 mm a week, but I didn't give that much leeway, subsequently borne out by the fact that it had taken almost two years to grow ten inches. I used to say to myself, "Come on you B.....r, grow" every time I was in 'will-power' mode.

You can imagine my joy, when about eight weeks after my operation, following many hours of willing the nerve to re-grow, I suddenly realised that I might have a little dampness in my dry eye. I would put a tissue to my eye to see if any dampness appeared on it. Initially and for a number of days, there were no marks on the tissue, although my eye felt as though it had moisture in it. Then one day, there it was, the tiniest mark of a teardrop. I was over the moon. If I could have had one post-operative wish, it would have been to have tears back in my damaged eye. To have dry eye, as most patients would no doubt agree, is one of the most difficult post-operative legacies to live with.

In readiness for when my nerve would re-grow, I decided to utilise a Trophic Unit, which gives pulses to wherever on the face the electrodes are placed. I purchased one about four weeks after my operation, and used it for at least three hours every single day for just under two years. I never missed a day in all that time. The idea, as I saw it, was to keep the face muscles toned up, in order that the nerves had something to attach to, once they reached the face. I was totally dedicated to its use every day as I was convinced that I would get the nerves to regenerate at some time in the future. And fortunately they did.

Whether the muscles would have been in a suitable condition to receive the growing nerve, without using the Trophic Unit is possibly open to debate, but I personally found it to be of immense benefit, and one of the reasons for the successful re-growth of my nerve.

At times it was exceedingly difficult to fit in three hours of usage every single day, but somehow I managed it. Mainly I would utilise driving time available during the day, particularly on long journeys. I even utilised the flying time when on holiday in America. Sometimes to find suitable time was difficult and I often used the Unit into the early hours.

Unfortunately, not all my face nerves have found their rightful positions, but my mouth is virtually straight, and the face crease up to the nose has reappeared. I can also curl my upper lip on the damaged side and recently noticed quite a

bit of movement around the eye. I keep working the muscles as often as I can and am still 'willing' the eye to be able to blink. To get it to do so would give me ultimate satisfaction.

As I have previously mentioned, I still have a little way to go, and I am under no false illusions that my face will ever grow back perfectly. However the nerve has regenerated over most of my face, and I am convinced that it was the use of the mind, and the continual daily effort, both mentally and with the use of the Trophic Unit, that has brought it this far.

It could of course just be Mother Nature doing another wonderful job, but I derived considerable satisfaction and comfort by believing that it was the power of the mind that helped re-generate the nerve, and I hope that other patients could do likewise, after reading my experiences.

Wax & Digital Hearing Aids A cautionary tale

Like most of you, I am unable to hear any speech in my "AN ear". Over the past few years my so-called "good ear" has gradually been unable to live up to this name. Consequently I was prescribed a standard NHS hearing aid which dramatically helped my hearing. However, I still could not cope at all with background noise.

Realising that my hearing will not improve and that hearing aid technology is improving, I decided to invest in the most effective hearing aid available. I looked through as much literature as I could find then contacted a hearing aid dispenser. He recommended the "latest" digital hearing aid: a nine channel completely in the ear canal (CIC) with the facility to be programmed to my specific needs.

During the trial period, I wore it for short periods of up to an hour each day in order to get used to it and afterwards cleared it of any wax as recommended by the dispenser. Finding it was a significant improvement, I committed myself to the required £1800 at the end of the trial period.

Subsequently, I wore the aid for most of the day but then found after wearing it for one or two hours it was prone to stop working as it became blocked with ear wax. A minute or two clearing away the wax was all it required and then all was well again. By the end of a month or so, I was getting fed up with this ritual. Eventually, while clearing it, a "tiny spring" shot into outer space. It would no longer work. I returned it to its pouch and rang the dispenser.

Meanwhile I looked again at the handbook and to my surprise saw that there was a small device for catching wax. There was no such device on my aid. The dispenser

returned in less than a week with the aid in working order again. Upon registering my complaint, he replied that my ear canal was too narrow and that there was no room for this device.

As the aid continued to give up intermittently, I then requested him to replace it with a "behind the ear" (BTE) version. He replied that it could not be exchanged and that I would have to pay for a new one. Feeling dejected, I contacted another dispenser who, without any prompting from me, advised me among other things about the hazards of wax with CIC aids. After explaining my situation to him, he continued to carry out a comprehensive series of tests and demonstrations including the "very latest" BTE hearing aid - a Resound 5. I was quite impressed with this aid, but instead of trying to sell it to me, he insisted that I go back to my previous dispenser and demand better service from him. I took his advice. The dispenser would not exchange it as it was long past the trial period, but offered me a Digital II Focus Power behind the ear aid, that is similar to the Resound 5 aid, for £850 which is a little below half its full price.

This new aid works very well although background noise still causes some difficulties yet, for me, is probably worth spending £2650; although it would have been more palatable without the extra £850.

I just wish the dispenser had advised me (like the other dispenser) against the hazards of narrow ear canals and ear wax and, in my case, recommended against a "completely in the canal" aid.

PS. I find my old reliable NHS aid is better for listening to TV as it has greater volume control so I can turn the volume up on my aid and down on the TV so I do not disturb others. For everything else including listening to music I wear my digital aid all the time (except in bed and the bath!).

Ray Maw

Snippets



I have a couple of tips from members which you may find interesting. Rachael Pearson has sent us another tip. Keep them coming Rachael - I'll have to give you a regular slot!

Are you bad-tempered at breakfast?

If this is because your head throbs even more than it did when you went to bed, then read on.

A friend I made on A3 and I both have chronic headaches as a result of our surgery. My friend Mary has discovered a product which has helped both of us to sleep better. It is the Anatomical Neckcare Pillow and comes. Believe it or not, from Argos. Current price £9.25. It takes a little getting used to as it is not squashy like most pillows, but anything that enables me to get up in the morning is well worth the effort.

Today I was even able to regress to adolescence by watching a video of 'The Graduate' while eating toast. Now that's progress.

Sandra Coles has written in response to Rachel's piece in the last newsletter

In response to the article 'Down in the mouth' I also have reduced flow of saliva following acoustic neuroma surgery. Recently a doctor prescribed me a synthetic saliva. This product is called Glandosane and can be purchased over the counter of the chemist priced £6.96. This is for a 50 ml aerosol spray which can be carried easily.

Glandosane can be used as a replacement for natural saliva, it is more effective and longer lasting than drinking or wetting the mouth with water.

I have found this product extremely helpful during the night, and on car journeys, and it will not give you tooth decay.

On another note I have started lip reading classes which I feel may help me at dinner parties and social events which are noisy. I was told by the tutor that there are classes in most areas and details can be found at your local library. The cost for the year is £11, many of our members could benefit from the classes.

So beware - you will have to look away now if you want to talk about me.

Kind regards to all our readers
Sandra Coles

I am also including another update on Vislube from Ray Maw in this column

Visulube Update

I have now received 27 completed questionnaires from members including 7 from BANA members. Just over half said they found Vislube better than other medications they were using.

Of those saying they **would not** consider using Vislube, most said that they need ointment or that it does not stop their eye getting sore. A few said it makes their eye sting or go red. A number also found it is inconvenient to use.

Of those saying they **would continue** to use Vislube, most felt it is soothing and avoids the blurred vision experienced with using ointment. One said "it is far more effective in clearing my eye and keeping it so" while two others said "life has improved dramatically" and another is able to drive his car again.

I am now supplying Vislube to 16 members on a regular basis at approximately £4.50 per box of 20 mono-doses including packing and postage.

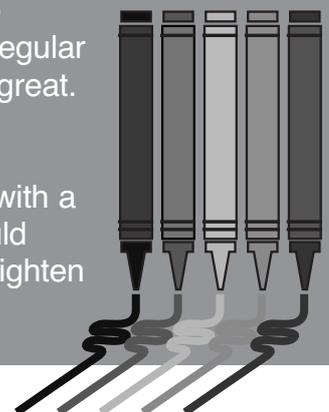
The recent AMNET Membership 2000 Survey indicates that over half of you (58%) have dry eyes and exactly half of you with dry eyes find it troubles you "quite a lot" or "very much". *While not everyone finds Vislube is helpful to them, you might wish to find out for yourself. If so, let me know and I shall send you a free sample.*

Ray Maw Telephone: 01787 248036

Illustrations

Is there an artist or cartoonist out there?
If so - your newsletter needs you!

I would like more illustrations for the newsletter and a regular cartoon would be great. Also good quality photographs, particularly taken with a digital camera could also be used to brighten up our pages.



postbag



I have a few letters this time which is great - please keep them coming! I make no apologies for the first two as I think we need to be aware of what people think of AMNET and also maybe the people we are not reaching at present and should know of our existence.

This first letter was written to Ray Maw after he provided information and is one of a number of similar letters he has received thanking him for his help.

The information supplied was helpful, but way too late! I discovered AMNET a year after my operation, whilst browsing the internet at random.

The information would have saved a lot of worry and confusion if I had received it prior to surgery. At no stage prior to or after the operation was I made aware that AMNET existed!

Presumably I 'fell through the net' because I had a brain tumour (Glomus) rather than an acoustic neuroma, but the surgery and symptoms are the same, as are the side effects! Those patients under joint ENT and neurosurgery have no support group.

I feel strongly that both Mr Moffat and Mr Hardy and their respective departments should hand out an AMNET leaflet to all newly diagnosed patients, and not just those with an AN! This would save a lot of fear and heartache. I felt very 'alone' during the entire process, which I would not have done if I had known AMNET existed. Please pass on my comments.

Lindsay Bang

Whilst waiting in Clinic 10 at Addenbrooke's recently, and only because I am of an observant nature, I espied the words 'Acoustic Neuroma on a leaflet pinned to the notice board behind me! Being an Acoustic Neuroma patient I pounced on this publication - AMNET NEWS - which I found most interesting and highly informative.

Although I have been a AN patient for over ten years now I have never heard of this publication, or of the organisation BANA. I feel an excellent publication such as this should be in a more prominent position, say copies at reception or mailed to appropriate patients with their appointments.

I noticed there was a website address, but being one of the majority of people without a home computer, this information was of no use.

Betty L

These two letters, and there have been other similar ones, highlight the fact that there are a number of people out there who would like to know about AMNET but have never heard of us. New patients visiting clinic are now given a booklet about acoustic neuroma which contains information about AMNET, but there are still many past patients who do not know

we exist. The committee are looking at ways of reaching these people. The website is proving to be a useful source of contact, but as Betty says not everyone has a computer. Other forms of information in strategic positions should help.

Jennifer Elliot de Reverol has written from the Canary Islands in response to our last newsletter.

I have just received the latest AMNET NEWS and thought I would make a contribution, giving you the latest news about my progress, in the hope that it will be of some encouragement to others.

It was interesting to read about the Gamma Knife approach, which has received so much publicity recently.

Whilst agreeing with several comments about patients not being given pre-op information which they had not requested, I personally felt I needed as much information as possible in order to psychologically face up to and understand more, what was about to happen to me. As I was going in to have mine I came face to face with and talked to someone who was just going home after his operation. Undoubtedly, everyone's need is different and we all have different ways of coping.

I had a Fisch type C.Glomus Jugulare tumour removed by Mr Moffat and Mr Hardy in May 1998. Everything was fine following my first yearly check up but shortly afterwards I noticed a pulsating sound on the affected side. This had been the original symptom which had led me to suspect I had a problem in the first place. Following a scan I was given the all clear, there was no sign of tumour re-growth.

So here I am, two years on, leading an active life, which entails having a full time teaching job and coping with two teenage daughters, a husband and numerous animals. I am lucky to have the same hearing as before the operation and I have no facial paralysis, drooping mouth or dry eye. I do have a bald patch on the back of my head and a numb calf. I also suffer from tiredness and poor sleep sometimes. However on the whole, I feel very well.

I'd be glad to share your thoughts, problems and so on. Keep up the good work all of you!

Jennifer Elliot de Riverol

Thanks for your letter Jennifer - I suspect living in such a nice climate must help a little! However I am grateful for your comments on issues raised in the last newsletter. What do the rest of you feel about the availability of information to people waiting for their operations? I suspect we may have a biased membership, but I would love to hear what you think.

Ed

Surfing the Net?



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 cassette 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

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

19th January 2001



AMNET Advisory Panel at Addenbrooke's Hospital

Mr David Baguley MSc MBA
Principal Audiological Scientist

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

Emma Stanton RN
Clinical Nurse Practitioner

Sue Woodford RN
Staff Nurse Clinic 10

FORTHCOMING MEETINGS

The next meeting will be on **Saturday 9th December Boardroom, Addenbrooke's Hospital Doors open 12 noon**

The speaker will be **Mr David Baguley MSc MBA Principal Audiological Scientist**
We will also have a representative from CAMTAD with a selection of aids for people with hearing problems.

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

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.

Apology from Alison and the committee

An apology for having to cancel the September meeting, due to the fuel crisis. I thought it was safer so that no-one got stuck half way there or half way home! We will re-schedule Mr Sarkies for the Spring meeting 2001. I hope to see you all at the December 9th meeting

Please bring a contribution of food so we can all share a seasonal lunch. There will be a raffle this year, but the committee have decided not to ask for contributions as we were overwhelmed last year, so just come along prepared to buy lots of tickets!

Spring Meeting

The speaker will be **Mr N Sarkies MRCP FRCS FRCOphth Consultant Ophthalmic Surgeon** who will talk about dealing

with eye problems following skull base surgery

Date to be confirmed

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.

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