

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 2002
Issue 24

Wishing all our members Happy Christmas and Best Wishes for the New Year

BANA's 10th Anniversary



On Saturday 19th October Alison and I found ourselves heading for Birmingham. We had been invited to BANA's 10th Anniversary celebration being held at the Hilton Metropole Hotel at the NEC.

It turned out to be a rather grand affair. The hotel was very impressive and the event was held in a large conference room with scattered tables each sporting an attractive flower display. There were over 200 people there from most of the branches of BANA.

The compere for the afternoon was Steven Howe who introduced Malcolm Hebdon (better known to most of you as 'Norris' from Coronation Street) who officially opened the proceedings. He said he was a friend of one of the early members

of BANA, the actor Chris Gray, and that four other friends of his had undergone brain surgery. He said what they had all wanted was information about the operation and recovery period. BANA provides information to patients, relatives and friends, information which is very much needed. So he congratulated BANA on 10 years of providing this service. He also, as a parting gesture, thanked Rita for giving him the day off from the Kabin! *(We have a photograph of your chairman with Malcolm just to prove we did meet him!)*

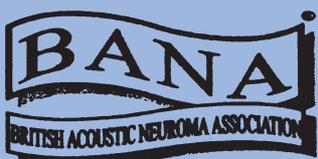
Colin Dawes, chairman of BANA gave a review of the last ten years. In the beginning a group of patients and carers met in a Nottingham hotel, brought together by a neurosurgeon and ENT surgeon from Nottingham. Aims and objectives and a constitution were set up and in 1993 BANA gained charitable status. The main aims of BANA are to relieve infirmity and suffering of people diagnosed and treated for acoustic neuroma and to

promote research into treatment and rehabilitation. In 1996 BANA received a grant from the National Lottery Charities Board which enabled them to set up an office with a full-time co-ordinator in Mansfield and also to buy 23 trophic stimulators which would be loaned to members with professional support from local physiotherapists.

There are currently 19 branches of varying size and activity around the country which are recognised as the organisation's most valuable asset in helping people. Over the years BANA has produced a number of booklets and other sources of information including a website. They belong to an umbrella organisation called the Neurological Alliance which has direct contact with the Department of Health and can influence policy. The members of the organisation are it's most important asset and numbers continue to increase widening the support which can be offered. Colin recognised

Next Meeting

The next meeting will be on Saturday 7th December 2002 in the Boardroom at Addenbrooke's Hospital. Doors open 12.00 hrs.



the work which had been done by volunteers through the years including : Sheila Atkin, Sue Clifford, Yvonne Colbourne and his wife Christine Dawes who has been Treasurer since the beginning of the organisation. Colin then introduced the new video which has been produced by Simon Gallimore and Nancy Phatt from an organisation called the Media Trust which is a non-profit making charity which produces videos for other charities. The video has been financed by the Lloyds/TSB Foundation. We were shown the video which is designed to be loaned to people who have been told they have acoustic neuroma and it seeks to reassure people and explain the various options and treatments. We were impressed by it and hope to have a copy to show you at the Christmas meeting. It's called 'Don't Panic – Acoustic Neuroma explained'

We then had a break when we were served with a substantial buffet and were able to mingle.

Following the break Diana Farragher presented awards to all the branch leaders and other committee members who have given time and effort to BANA over the years. The entertainment for the evening came from Grant Baynham (from 'That's Life') who entertained with a mixture of folk songs, satirical ditties and some very impressive guitar playing. The evening closed with a word from the sponsors of the day Entific who make bone assisted hearing aids and promote them for sufferers of single sided deafness. The aid consists of a small transmitter which is implanted in the skull and with a receiver worn behind the ear is able to transmit sounds from one side to the other. Further information is available from their website www.patients-baha.com, or www.entific.com.

Alison and I headed home after what had been an interesting and enjoyable afternoon and we wish BANA all the best for the next 10 years!

Christmas Cards

If you are not so well organised that it's too late you may be interested to know that BANA has produced Christmas cards again at a cost of £4.99 for 10. We will have pictures of the designs and order forms available at the Christmas meeting.

BANA have also sent us some Raffle tickets for a draw on December 7th. If you would like to buy or sell some, please contact Alison.

Jubilee Garden Appeal at Addenbrooke's (from Addenbrooke's Matters)

Addenbrooke's Hospital has celebrated the Golden Jubilee by creating a unique garden retreat for it's many patients, visitors and staff. The garden is situated at the heart of the hospital and is accessible to all users, including those using wheelchairs. It forms the entrance to the Children's Day Unit and is close to the Rehabilitation and Stroke Units. It is also overlooked by other patient areas.

The garden has a pergola with climbing plants which will provide shaded and scented areas to sit. A new central 'sociable' area will be created with improved paths and a raised bed. Imaginative planting will provide interest for all ages and at all times of the year. The garden will be used by patients learning to walk again and by elderly patients who want to practise their gardening skills. Musical and other artistic events will be held here – it is hoped that this area will be appreciated by thousands of people for years to come.

The garden is being designed and created by patients, volunteers and staff. We need funding to build, plant and provide high-quality seating and artworks. We know that an enriched environment aids patients' recovery – this garden will also make the hospital a better place to work and visit.

Alexandra Rose 'Rose'

Alexandra Rose Day is a charity which helps other charities to raise funds. We have sold raffle tickets on a number of occasions and much of the profit goes to us. The organisation are launching a new rose called 'Rose Ball', which has been bred by a local nursery – Peter Beales Roses' in Attleborough, Norfolk and can be ordered from their catalogue (Tel: 01953 454707). The rose is a shrub rose with soft, powder pink fragrant double flowers and £2 will go to the Alexandra Rose Day charity for every rose sold in 2003 and after that £1 per rose. If you are looking for a new rose for the garden, maybe you would like to consider this one

Mum wins prize for her bravery

This report was in the August edition of 'Best' magazine and also in the Eastern Daily Press



Picture reproduced with permission from Best Magazine

When she was diagnosed with a brain tumour at around the same time her only daughter fell pregnant, Karen Hardesty was faced with a heart-rending choice. She had to decide whether to go ahead with life-saving treatment or postpone the operation and keep a promise to be at the birth of her first grandchild.

For some, it would have been a tough decision, but Mrs Hardesty did not hesitate; she cancelled her operation to help her daughter, and now she has been rewarded by scooping the title of 'Brave Mum of the Year'

Her daughter Tracey Oakley, 22, found out about the baby soon after splitting with her boyfriend. She was frightened of being alone at the birth and of being a single mother, so Karen promised to help her through it and share the care of the baby.

The tumour was diagnosed around two years ago after Karen, 47, was referred for a brain scan following dizzy spells and the loss of hearing in her

right ear.

'The consultant said that although the tumour wasn't cancerous, I'd need a 10 hour operation to remove it.' said Mrs Hardesty, who is married to Brian and also has three sons.

'The tumour was growing all the time and might invade my brain stem, which could kill me'

Addenbrooke's Hospital in Cambridge had arranged the operation to remove it to take place in October, the same month as Tracey was due to give birth.

'Postponing my operation could kill me, but I had made a promise to my daughter that I was determined to keep' added Mrs Hardesty, who lives in Long Stratton, Norfolk.

Tracey gave birth to Jamie-Lee in October and for three months Karen helped to look after the baby before finally going in for the operation on January 29th last year - eight days after her first grandchild was christened.

Mrs Hardesty thinks the baby helped her recover from the operation which doctors said was a success. 'Jamie-Lee is the best tonic I could have asked for,' she said

Tracey was so proud, she entered her mum in the bravest category of Best Magazine's Britain's Mums of the Year competition.

Tracey said: 'Mum is the bravest person I know. I begged her to have surgery in October, but she put aside all her fears to be with me and the baby. I don't know what I would have done without her support. She is one in a million!'

As a category winner, Mrs Hardesty received a £1000 prize from womenswear retailer Bonmarche plus a makeover by the magazine's beauty and fashion teams.

Editorial

Dear all

Happy Christmas everyone - maybe I will be the first to bring you seasonal greetings. This newsletter has reports of a couple of interesting and enjoyable events which I hope those of you who couldn't attend them will catch a flavour of. We also have a report of one of our members winning a national award for bravery which makes inspiring reading. What we don't have this month is a Postbag or Rachel's Corner as we haven't heard from anyone so please, please let us hear your thoughts on anything at all that you think might interest other members.

Best wishes for the New Year

Chris.

'VISIBLY DIFFERENT'

A TALK AND DEMONSTRATION FROM NORMA GAYE

Unfortunately I had a double booking and only managed to attend the last half hour of Norma's two sessions so I am very grateful to Alison, Jill, and Anne who have taken time to write their impressions of the session for me and thereby produced a much more interesting report than I would have written!



This is Alison and Rebecca's report

'Mum can I come with you tomorrow, what's it about?

'Style, colour and makeup'

'Sound good, I'll come and sit at the back'

The above exchange took place on Friday September 20th. On the following morning my 13 year old daughter, Rebecca, and myself set off for Addenbrooke's and met Norma Gaye as she was unloading her car. Small car, lots of makeup cases, boxes and short square stands. Norma at first sight is simply, but beautifully dressed, warm and looks full of vitality. When we got to the boardroom we positioned a large table at the front and then broke up the rows of chairs so the room looked more friendly. Norma could then move around more easily so she set to work filling the short, square stands with swatches of material in every colour and shade.

Once the meeting started Norma covered up the clothes her two models Anne (blonde) and Rebecca (red haired) were wearing and put swatches of clothes over their shoulders. By putting them close to their chins with a white background we began to see which colours flattered and which detracted from natural skin colouring. Even different types of white and cream and shiny and plain made a difference to complexion. Everyone fits into one calendar seasons colours with slight nuances.

Our speaker worked her way around the room looking at faces, some with problem areas, some not, suggesting assorted colours and hues. The men were not forgotten with ideas for pink shirts and white T shirts so people who were anxious about their appearance didn't 'disappear' into dark colours. Some members were surprised by ideas 'I've never worn that colour - maybe I'll try it!'. Norma emphasised the importance of taking the gaze away from a perceived problem area so the correctly sized pretty earrings or a brooch on the shoulder would deflect attention. For the men the top of a hanky in a jacket pocket or a motif at the side of a T shirt might help. Attention to hairstyle to broaden or lengthen the face is also important. In the afternoon Norma spoke about makeup and the importance of looking after skin, both cleansing and moisturising for **everyone**. This is easier now it is more 'acceptable' for men to take an interest in skin care.



Demonstrating on various members, Norma showed us how to use concealer stick to balance our faces and detract from problem areas. Blusher was recommended for most people, it helps us to look healthier. Using an intermittent eye pencil line under the 'big' eye to the middle of the eye and an unbroken line under the small eye also helps balance.

After the afternoon session members could talk to Norma about their particular problems. I felt it was positive to have something pleasant done to our faces and images after all the unpleasant

procedures some of us have had to go through. Norma carries out a lot of work with Diana Farragher and I can see why. Thanks Norma for a great day!

Jill has provided her view of the sessions

There was probably a fair degree of scepticism in the audience as Norma began to talk to us on the subject 'Visibly Different' - an exploration of how the colours we wear can change the way we are perceived. The evidence of our own eyes however, rapidly won over the cynics amongst us, as with two very good hearted volunteers, she showed us how wearing the wrong shades can drain our faces and emphasise our worst features. In this instance the proof of the pudding was literally in front of us - (and the writer of this is an example). It's no good wearing solid harsh black for instance, (however fashionable, however chic,) if it leaves you looking gaunt and funereal, whilst the right colour can knock years off your age or restore your cheekbones. It seems to be a subtle science though - nothing as simple as light versus dark. For example, Norma compared 'clinical white' versus 'soft off white' - a pretty nice distinction you'd think, but the results, as demonstrated, were very different. Some of the definitions might have been a bit 'new age' for some of the audience perhaps - are you a 'Summer' person for example - and if so which month? And Gentlemen should wear pink? - well yes, as it happens, certain gentlemen should - the evidence of our own eyes was proof enough.

The afternoon was devoted to makeup - which might have made it pretty hard for the men to feel included, although Norma took time to

demonstrate some nifty tricks for either sex, using a concealer stick to lessen several of the more obvious effects of facial nerve damage. From there on, the makeup information was mostly aimed at women and fantastically useful it was. How to apply eyeliner, for example, in such a way that our eyes can look more symmetrical; how to use lipstick to negate the effects of a one-sided drooping mouth. The statistics tell us that women patients are more concerned than men, with the cosmetic effects of any facial nerve damage they may suffer from their operations: so perhaps it's not too unfair that it is women who also have at their disposal, the use of 'visible' makeup to come so effectively to their aid.

Anne was brave enough to be a model for the afternoon session - here are her thoughts.

Here are a few comments on being a 'model' at the visibly different talk. The colour experience was most enlightening, and although I discovered I should not wear black and pure white, [I came in a black top and white trousers!] I found Norma's honest no holds barred approach very instructive, and I agree with her that as a 'summer person' the pastel palette would be much more suitable for me. With regard to the afternoon make up demonstration, she gave helpful hints on how to try and hide bad points and make the most of the good ones. The final result seemed to meet with the approval of the audience but I felt it was not quite me for every day wear. But having said that, I have taken note of her advice and will experiment with different eye colours and will certainly make sure I wear blusher at all times! I wish to thank the audience for being honest with their opinions.



SNIPPETS

AMNET LIBRARY

MEMBERS' SURVEY 2002: Progress

Thank you yet again for your splendid response to our latest members' survey.

We have an 88% response so far and it's still rising. In addition, questionnaires were sent out to a number of former members and just over two thirds have responded.

This survey is an update of the previous surveys carried out in August 1998, August 1999 and August 2000. The aim is to discover the *"rates of recovery"* from the specific post-operative problems which you have had, to know which problems continue to be the *most troublesome* and to find *ways of coping* with them.

On this occasion, we also asked about employment to find out the impact of the operation upon our ability to continue working afterwards.

I am currently analysing the responses so far and hope to let you have the findings in future newsletters.

Many thanks again for your support.

Ray Maw

United Kingdom Brain Tumour Society Helpline

Following an invitation by the United Kingdom Brain Tumour Society (UKBTS) to join the national support helpline they are in the process of setting up, I attended on behalf of AMNET and Meningioma Association UK and took part in a training day in London on the 27th, September. There were around a ten people present, all of whom had close personal experience of a brain tumour themselves or in their families. The day was led by an experienced trainer from Cancerlink Macmillan and we looked at the range of telephone skills necessary to give support to callers. We also discussed the callers' needs and feelings, and how to respond sensitively and effectively.

UKBTS will act as the link between caller and helpline volunteer, and is keen to match the caller to a suitably experienced volunteer. They will also respond to requests for brain tumour information by sending out booklets and fact sheets prior to putting the caller in touch with a helpline volunteer.

At the meeting and also subsequently, I made sure that UKBTS appreciated the depth of experience offered by AMNET and ourselves, and our willingness to offer support to any acoustic neuroma or meningioma patients who contact us.

Following their successful two day conference held in Nottingham in July this year, UKBTS is keen to explore further the possibilities of partnership of the many brain tumour charities around the UK. Professor Geoff Pilkington, who was the main driving force behind the conference, said that he thought it provided a great platform to get the existing charities together to form a coalition - to raise the national profile of neuro-oncology and effectively lobby Parliament to provide better support for patients and improved research facilities and funding.

Ella Pybus

Your hospital notes (from CAMTAD newsletter)

Hospital notes are, naturally, confidential and it has been decided that putting ear stickers on the outside to advertise to all that you need help to hear is the wrong answer. Some people do not wish to advertise the fact that they have a problem to all and sundry. A new system has therefore been devised at Addenbrookes. Anyone with a drug allergy or who needs special help in any way will have two alert stickers on the outside of their notes in different places. Only authorised people will be able to look in the notes to see a special page at the front of the notes with a wide red border so that if it should be covered up by mistake it will be easily identified. On this page will be details of drug allergies or other life threatening details; also details of sensory impairment and other disabilities.



TELEPHONE SNIPPETS

BT's New Text Payphones (from Nf2 News)

BT is aiming to complete the installation and upgrading of 2000 new text payphones at various public sites across the country within the next few months. Each text payphone will offer email, Short Messages Services and access to the RNID Typetalk Relay Service using BT TextDirect. At the present time they do not allow you to use VCO (voice carry over) on a call. Text payphones have a larger screen than regular payphones and a standard keyboard instead of a dialling keypad. They are easy to use because they have on-screen menus which assist you as a call is being made. Because the phones cannot offer a cash rebate for the extra time taken to type the text part of a call, BT has increased the timespan of each unit, so that you get more time for your money. The payphones also accept return calls if someone wants to call you back, they can.

NHS textphone service (from CAMTAD Newsletter)

NHS Direct has introduced a single national textphone number for deaf and hard of hearing people on 0845 606 4647. The number connects callers to nurses who have had specialist training to help them meet the needs of textphone users. You can log onto NHS Direct at www.nhsdirect.nhs.uk.

Text Messaging

A comment from a recent copy of Nf2 News points out the usefulness of text messaging for those who are hard of hearing. Messages can be sent from anywhere and do not rely on being able to hear and only cost 10p. (*My new phone even guesses what words I am trying to put in - which is great if it's right, but I don't know how to change it if it's wrong!*) Anyway, for those of you who have not joined the mobile phone revolution yet this may be a reason to reconsider.

Meet your committee



Neil Bray **(New patients officer /co-opted committee member)**

Neil has been a member of AMNET since it's beginning, coordinating some of the patient visiting and offering help on the committee in various ways. He had his operation in 1993 at Addenbrookes. He lives and works in Cambridge sharing his time between a wife and three children (aged 5, 8 & 10) and implementing computer processors for the silicon chip industry. In his spare time he enjoys walking, photography and holidays which all combined nicely this year with a trip to the American "Wild West".



Tony Monk (Secretary)

Prior to taking early retirement in 1996, due to ill health, Tony worked as a Quantity Surveyor and was Director of Surveying for his company. He had his acoustic neuroma removed in July 1997. He made a good recovery and enjoys relaxing in front of most sport on television, working in the garden and visiting National Trust properties, and especially now he enjoys his new little grandson.



Eleanor Monk

Eleanor has also retired, having run a small catering and bed and breakfast business for several years. She is a very proud granny!



Ray Maw **(Information and Library)**

Ray joined AMNET shortly after moving to Suffolk following his acoustic neuroma operation at the Radcliffe Infirmary, Oxford in 1995. He took early retirement from his academic career in research and higher degree supervision to pursue private practice but had to abandon this as a result of the acoustic neuroma and heart operations. He now leads a more leisurely occupation making and teaching pottery. Not forgetting, of course, his dedication to providing information and support for members of AMNET through his extensive library and information service.



Jill Laurimore

Jill was co-opted onto the AMNET committee last year. She had a long career as a ceramicist and also an art dealer, before taking a sabbatical to try and write her first novel. Her diagnosis was made just as she'd had the book accepted for publication by Penguin. She finished editing it only days before her operation in 1998, and has since had two more novels commissioned by Penguin. She has two London-based adult daughters and lives in Suffolk with her actor husband Jon.

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.

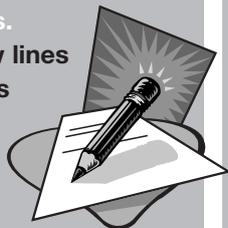
Contributions on paper and/or disc (Microsoft Word) to:-

Chris Richards

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

email: chris@richards2113.fsnet.co.uk

by: 31st January 2003



AMNET Advisory Panel at Addenbrooke's Hospital

Mr David Baguley MSc MBA
Principal Audiological Scientist

Jean Hatchell

Clinical Nurse Practitioner

Mr Robert Macfarlane MD FRCS
Consultant Neurosurgeon

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

Mr N J C Sarkies MRCP FRCS
FRCOphth Consultant Ophthalmic Surgeon

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

A Basic Overview of Diagnosis and Treatment of Acoustic Neuroma

The Facial Nerve and Acoustic Neuroma

Headache after Acoustic Neuroma Surgery

Eye care after Acoustic Neuroma Surgery

Balance following Acoustic Neuroma

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

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

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

Also [which-doctor.co.uk](http://www.which-doctor.co.uk)

The new web-site search directory to help you find a doctor with a particular skill, service specialist or research interest, anywhere in the UK.

<http://www.which-doctor.co.uk>

email info@which-doctor.co.uk

Addresses and Web sites

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

Changing Faces

(Registered Charity 1011222)

1-2 Junction Mews, London W2 1PN

Tel 0202 7706 4232

Email: info@faces.demon.co.uk

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

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

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)

4th floor, White Building, Fitzalan Square,
Sheffield S1 2AZ

Freephone enquiry line 0800 018 0527

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

The Meningioma Association UK

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

Tel: 01787 374084

Email: MeningiomaUK@aol.com

Facial Stimulators

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

BANA

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

Tel 01623 632143 Fax 01623 635313

Email bana@btclick.com

Library

Book Amnesty Alison is missing a number of books she has sent out over the years. If you have borrowed books from AMNET we would be grateful if you could check your bookshelves and return any books you may find. This can be done anonymously if you wish. We would just like to keep a good supply for new people who request information.

FORTHCOMING MEETINGS

The next meeting will be held on Saturday 7th December 2002 in the Boardroom at Addenbrooke's Hospital. Doors open at 12.00 hrs. Please bring a contribution of food to share with everyone. There will be a variety of entertainment on offer.

The April meeting is yet to be confirmed

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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