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Tireless work for others earns Civic Award



Cynthia and Geoff stepped down from MGA in July 2002 and have been given a Civic Award by Derby Council in recognition of all that they have done for people diagnosed as suffering from myasthenia gravis. We have paraphrased a report in the Derby Evening Telegraph on April 12th 2003.

Discovering that a member of your family has a relatively unknown disease can turn your world upside down. When Derby couple, Cynthia and Geoff Buckley were told in 1960 that Cynthia's mother, Mary Woodcock (picture above) had been diagnosed with myasthenia they had nowhere to turn. Forty years ago, little was known about myasthenia gravis, so Cynthia and Geoff decided to set up their own society to help fund research into the condition. After several meetings - the first of which happened in 1968 - the UK's first Myasthenia Gravis Association was born in Derby and in 1976 it became a charity.

And now the hard work and dedication of Cynthia and Geoff has been recognised by Derby City Council, which has given them a Civic Award. When being interviewed by the Derby Evening Telegraph reporter, Cynthia said :-

"When my mother was diagnosed with myasthenia, people did not really know much about it. We were handed a list of about 150 people who had also been diagnosed, so my husband contacted them and 99 per cent of them said they had not heard of anyone else who had the disease. It all started from there and we eventually become quite a big operation, so we moved into our first offices in 1987 in Nottingham Road, Derby, thanks to help from the Liversage Trust. The first Myasthenia Association was set up in America but we were the first one in the UK. The Charity's headquarters has been in Alfreton Road since 1994. MGA was run entirely as a voluntary organisation until 1988 but has grown, with branches across the country, dedicated to raising awareness of the disease and raising money for research. We are very grateful for the award, although I think it should be more for my husband as he has worked tirelessly in memory of his mother-in-law, who died in 1974".

For our part, we are immensely proud of what Cynthia and Geoff have achieved. The Telegraph article outlined the main events of how the Charity came about, but, of course, could not go into all the details of what has happened and the enormous undertakings that they have been involved in for some 35 years. We, the MGA, take great pride in them and are very grateful to Derby Council for giving them this award.

AGM 2003

The Annual General Meeting of the Myasthenia Gravis Association will take place at

Liverpool on Saturday 27th Sept 2003.

Details will be notified to those Members eligible to attend in due course. Please make a note in your diary for this important event in the MGA calendar.

Message from the MGA Chairman

Since my last message the MGA Board has met twice. After our meeting in March we held a full-day strategy meeting at which we discussed several issues of importance to the Association. Our general discussion headings were the future direction of the charity (the balance between our various objectives), the budget process and financial control, and the Association's Articles of Association and Rules. As a result of this last topic we will probably be asking members to approve some changes to the Articles of Association at the next Annual General Meeting. These changes will be aimed at removing some ambiguities and inconsistencies in the Articles, and will also allow the introduction of a more democratic process for voting by proxy at General Meetings. The next AGM, in September, will have to be held under the existing Articles.

The financial status of the Association is improving, but we still have some way to go if we are to be able to do all the things which we (the Board and Members) would like. The Trustees greatly appreciate the loyal support of the members and our staff, whose efforts have continued to grow

the fundraising at branch and regional level. For our part, we are doing our best to strengthen our financial controls, so that we can make the best use possible of the money which is raised. To this end the Board has set up a Financial Sub-committee, which will be responsible to the Trustees for discharging those functions.

Looking forward to the next AGM – there will be at least one vacancy for a member to be elected to the Board as a Trustee. If you are interested in serving the Association in this way, or you know of someone who may be suitable (and willing) please contact me or the Company Secretary for advice.

Best wishes to you all.

Peter Finney – Chairman of the MGA Board.

The Company Secretary can be contacted as under:

*The Company Secretary
Myasthenia Gravis Association
Springfield, Rookery Hill,
Ashted Park,
Ashted, Surrey
KT21 1HY*

An Update From Alasdair Nimmo (CEO)

Hello everyone, and a warm welcome to the latest edition of MGA News. May I especially welcome those new members who have recently joined the association and extend a very warm welcome to all our new Branches.

Keeping you up to date:

Our new literature starting with Vol 1 "A Medical Guide for patients with Myasthenia Gravis" is currently with the printers. We will send a copy to all Branch Chairs. Full details of the Information Pack Series can be found in the article from the Publications Sub-Committee in this newsletter.

I am pleased to report to you that the Association has forwarded a cheque to the value of £25,000 to Muscular Dystrophy that will aid the research programme, in addition to this we will be forwarding a further £75,000. This will continue to

support the research programmes that are currently underway, viz:

1. Molecular mechanism and disease models of inherited myasthenic syndromes. **Headed up by Dr David Beeson.**
2. Involvement of calcium permeability and desensitisation of human acetylcholine receptors in the pathophysiology of a congenital myasthenic syndrome. **Headed up by Professor Angela Vincent.**
3. Characterising pathogenic helper T cells in myasthenia gravis patients and assessing their suitability as targets for severe immunotherapy. **Headed up by Professor Nick Wilcox.**

Keep up the good work Oxford.

Yes we know we are early, but included in this edition is a page of self-adhesive labels which you can use this Christmas to help us to raise the awareness of the Association. Simply peel off and insert into

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any Christmas Cards or presents that you will be sending. These stickers will work well with purchases made from the mailing of the Fundraising Direct catalogue that will be coming your way shortly. Hang on to your stickers until then. Our thanks to them as they are sponsoring the mailing, and don't forget 25% of what you purchase from them will come back to support the charity. While on the subject of Christmas we are currently work-

ing with Muscular Dystrophy to produce a joint selection of Christmas cards this year that will support you, your families and the Association. Further details in the next Newsletter.

Kind regards to you all
Alasdair Nimmo
 CEO

BRANCH POSTAL AREAS and FIRST CONTACTS

Many of the branches will know that we have been working very hard over the recent months to improve on the service that we can offer branches both in terms of administering their branch 'membership' and in providing support for the provision of listings, labels and mailings.

We are eventually beginning to achieve these objectives and it is all thanks to the support and encouragement that we have received from many branches and individuals throughout the UK. By now, all branches should have been contacted by their respective Regional Organiser (RO) to agree precisely which postal areas they wish to take responsibility for as far as their branch is concerned. There will inevitably be some overlap in the initial stages but we would encourage all branches to agree between themselves where their boundaries end and the neighbouring branch's commences. Your RO will be able to facilitate this for you. ***We would like to emphasise that it is for the branch to say which postal areas they wish to cover.*** We in Support will not impose any postal areas on the branches. However, where two or more branches **insist** on covering the same postal areas, they need to be aware that people living in these areas will receive multiple mailings both from the branches concerned and also from the ROs where conflicting branches fall into different RO Regions. Obviously, this is a waste of money and could be irritating for the person receiving the mailings, so we would strongly encourage all branches to speak to each other and agree where their boundaries lie.

NB. A postal area, for these purposes, consists of the left part of the UK postcode up to the space. I.e. 'DE21', 'DE24', etc. This is a small enough division

to be a workable solution but not so complicated as going right down to the next level - eg, 'DE21 4', or 'DE24 7', etc.

Please help us to help you and help the person suffering from MG, by taking a positive attitude to this initiative. We would ask that branches discard any historical references or boundaries and look at this afresh. The ROs are there to help you. Please make use of them.

Could we further ask all Branches to nominate a person in their Branch to act as First Contact and notify Support at Derby accordingly. Once we have resolved all the postal areas for all the branches, we will then be in a position to look up the details of the Branch's First Contact and notify newly diagnosed patients of these details when they come onto our database and are sent an Information Pack.

Thank you all so very much for all the work and effort you are putting in to help us get this right.

MESTINON Prolonged Release 180 mg Tablets

We have been advised by ICN that the Mestimon Prolonged Release Tablets (180 mg) are now available for prescription on a named patient basis from your consultant.

It is understood that these are not suitable for all people under all circumstances and therefore it is essential that you discuss your personal circumstances with your Consultant before taking these tablets.

**A new test for MuSK antibodies
is now available**
Prof Angela Vincent
MG Centre, Oxford

As most of you know, the weakness in MG is caused by defects in the nerve → muscle 'ignition system'. Usually, there is an immune attack on the muscle surface near the nerve endings; it causes loss of the 'ignition locks' (the acetylcholine receptors or *AChRs* for short). These *AChRs* crucially make sure that your muscles contract when you tell them to. Most patients with typical generalised MG weakness have *antibodies* that latch onto the *AChRs* and destroy them. These antibodies are routinely measured (with radioactive *AChR*) in many diagnostic labs. In Oxford, we test about 100 blood samples a week; the positive cases (about 1 in 10) can be given a firm diagnosis of MG.

We have known for a long time that about 12% of patients with typical generalised MG do not have antibodies against *AChR*, and are misleadingly called 'antibody-negative'. In fact, they clearly get better with plasma exchange and steroid treatment, just like typical MG patients, so they must have *some other harmful* antibodies. These can be transferred from MG mums to their developing babies, occasionally causing weakness in them – again as in typical MG.

In the MGA News (June 2001 Edition, P12), we said we had identified a new target for these antibodies, a different protein called MuSK. This MuSK is important because it helps the muscles cluster the *AChRs* opposite the nerve endings (see David Beeson's diagram on P5). We have found antibodies against MuSK in about half of the previously 'antibody-negative' patients – ie about 6% of all MG patients. Interestingly, we find antibodies against *AChR* or MuSK in completely separate patients, so there must be at least two distinct types of MG. We are now trying to learn more about the antibodies against MuSK, and to see if there is anything different about the myasthenia – or its ideal treatment – in the patients who have them. So far, it seems that they often have particular trouble with swallowing, speaking and chewing, and never have a thymoma.

After cloning the gene and mass-producing MuSK in cultured cells, we now purify it in small amounts. We make it slightly radioactive and then

use it to measure the antibodies. Over the last year in Oxford, this test has given very clear results and thus a firm diagnosis for more patients. It took some time to get commercial companies involved, but RSR Ltd (Cardiff) will start producing a "kit" in the next month or two so that other labs in the UK or Europe can measure the antibodies. RSR will also sell this material to the Athena Diagnostics labs in the USA, to allow them to test patients on that side of the Atlantic.

Doctors who need this test should send 1 ml of serum in a screw-topped polypropylene tube (double packed for the mail) to **Prof Angela Vincent, Neurosciences Group, Weatherall Institute of Molecular Medicine, John Radcliffe Hospital, Oxford OX3 9DS**. I'm afraid we have to charge £30 per test to help cover the costs. Any profits go into our research – not only for this form of MG, but also to help identify the target for antibodies in the mysterious remaining 6%.

**NEW PROGRESS ON THE
INHERITED MYASTHENIAS**
**A new National Diagnostic and
Advisory Service for
Congenital Myasthenias**
Dr David Beeson
MG Centre, Oxford

Your long-standing – and greatly appreciated – support for research into the inherited ('congenital') myasthenias has been rewarded by the Department of Health. It is now funding our new diagnostic service (in Oxford) for these rare forms of myasthenia through NSCAG (National Specialist Commissioning Advisory Service). Previously, this work was funded out of MGA/ Muscular Dystrophy Campaign research grants. The funding from NSCAG pays for:- (a) assessment of suspected inherited myasthenia patients at the Oxford Myasthenia Clinic (unfortunately this does not cover travelling expenses); (b) the considerable costs of screening their DNA to identify the exact genetic change that is to blame. If / when faults are identified, the families are invited back for further counselling and advice on treatments. It is already clear that faults in at least seven different genes can cause inherited myasthenias. At pre-

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sent, we screen only the most commonly affected gene in the NSCAG lab (the one for the 'epsilon' chain in the acetylcholine receptor [AChR]), and the other six genes in my research lab in the Neurosciences Group (Weatherall Institute of Molecular Medicine, Oxford). Over the next few years, we plan gradually to transfer all this work to the NSCAG-funded service. That should free-up all our research funds for searching for faults in new genes, for understanding how they cause weakness and for devising and testing new treatments.

A New Gene Involved in Inherited Myasthenia

The seventh gene was added to the list only in the last year. In most cases of inherited myasthenia, there are simply too few AChRs on the muscle surface, and triggering is inefficient. In about 3/4 of these, that is caused by small but crucial changes in the structure of the AChR itself. Many of the remaining 1/4 now turn out to have faults in a separate gene for an 'anchoring' protein called Rapsyn. The human version of this gene was first cloned in my lab; together with MuSK, it helps to cluster the AChRs tightly right opposite the nerve endings.

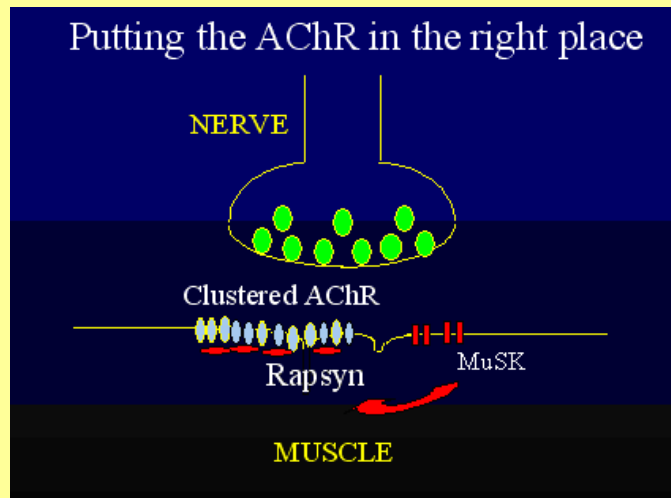
Diagram of a nerve → muscle junction.

Special signals from the nerve stimulate MuSK and Rapsyn (red) to cluster the 'ignition ocks' (AChRs) opposite the nerve endings. They keep them tightly packed there, ready to trigger the muscle whenever electrical impulses (from the brain) release showers of 'ignition keys' (ACh) from their stores (green bubbles) in the nerve endings, 'keys' that home into the AChRs to 'start the engine'.

Because of the Rapsyn gene faults, there are again too few AChRs in the right place. However, detailed scrutiny of these patients has revealed some interesting differences from those with AChR defects. If the Rapsyn is faulty, the myasthenia often gets gradually less severe by the age of about 8, and is usually only mildly disabling in adults. However, these same patients may previously have had serious trouble at birth and during their early years. Some even have bouts when their breathing is feeble; they are often brought on by throat or chest infections. Parents and other carers can be trained to cope with these potentially dangerous episodes quite easily.

Whereas the weakness is usually rather stable if the

AChR loss is due to faults in the AChR itself, it can be quite mild and come on only in adulthood in a few other cases with Rapsyn defects, even when their faults seem identical to those in the severely affected infants. That strongly hints that there must be other influences at play; if only we could identify them, we might be able to turn them to some patients' advantage. Finally, the late-onset weakness in the mild cases can easily be mistaken for autoimmune 'antibody-negative' MG – which underlines the importance of specialist assessment and clear diagnostic tests.



A new antibiotic you may need to be aware of Dr David Hilton-Jones (Oxford)

Many readers will know that some drug treatments can make myasthenia worse. Amongst the commonest are certain antibiotics. **If the myasthenia is well controlled**, they rarely cause problems; **if it is not**, they can do so, especially if a myasthenic crisis has been brought on by an infection and one of these antibiotics has been used to treat it. With most drugs, only a minority of patients reacts badly.

Another name has now been added to the list of drugs reported to worsen myasthenia. Aventis, the manufacturers of **Telithromycin (Ketekâ)**, have informed health professionals about this new anti-

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Letters are published as-is without any recommendation as to their suitability or accuracy.

The opinions expressed are entirely those of the contributor.

Care should be taken if following any advice or suggestions presented and it is strongly recommended that the advice of your GP or Consultant is taken in all cases.

Please Note: MGA reserve the right to open any letters which are sent to MGA to be forwarded on. This is to prevent the recipient being upset by receiving unsuitable mail.

Dear Editor,

I have found the Newsletter and the back copies that have been sent to me very useful since my diagnosis with MG last year at the age of 56. I have also met members of the local branch of MGA who are very helpful and supportive. May I pick up on a point that Gravis made in the Spring 2003 newsletter? He overheard somebody saying that they resented being called a 'Myasthenic'. I was pleased to discover that I am not the only one to hold that view because one of my earliest reactions after my diagnosis was to dislike being referred to as a 'Myasthenic' and I had wondered if anyone else felt the same way. This is my own view as I believe 'each to his own', but personally, I don't like being labelled in this way. I'm a person with myasthenia gravis. It is an illness I have but I'm not a new species since my diagnosis. Correct me if I am wrong, but I cannot think of another illness where people are labelled like this any more. The terms I can think of have been abandoned and, in my opinion, the word 'Myasthenic' is in the same league and should be phased out. Thanks, Gravis, for letting me know at least one other person feels the same as me.

Your sincerely

Diana Pallet, Ryde, Isle of Wight

(Ed. In keeping with Political Correctness, we have changed our front page which used to say "Keeping myasthenics in touch" to now read, "Supporting Those Diagnosed With Myasthenia Gravis". Our Literature follows suit)

Hello to my Fellow Myasthenia Gravis Sufferers, My name is Vera Jones. I thought I would write this letter after reading the letter sent to you by Caroline Simpson. She put into words all the feelings I had when I was diagnosed with MG many years ago. It was 1961 and the illness was practically unheard of then. I was 24 years old and had been married just a few weeks. My husband and I had moved to a new area away from all our relatives and friends. We had bought a new house and were happy in our jobs, and everything seemed wonderful. It was then I started to get the symptoms of our old friend MG. It took the doctors about six months to diagnose the illness. At first I was just glad to find out what was wrong with me,

but of course I couldn't have possibly known what was in store. Once I started to have some treatment, things improved. Then in 1962. I found I was pregnant; I had my baby. The baby was well but the birth and looking after the baby took its toll on my health as I had no one to help with the baby. My husband had to go to work, and my family lived too far away so things went from bad to worse. Finally in 1965 when I was at my weakest, I was told that the only thing they could suggest was a removal of my thymus gland. I had this operation just before Christmas 1965. Although I didn't know it at the time, it was the best present any one could give me but it took me about two years to recover. I was able to manage on a lot less medication and I was able to take my son out and start to enjoy life again. In 1968 I started to get some of my symptoms back and I was very worried. I soon found that the reason for the return of the symptoms was that I was pregnant. I had a baby girl. This time the hospital made arrangements for me and provided lots of help in looking after the baby. Both my children are healthy. My son is now 40 and my daughter is 34. Although I still need to take my Mestinon, I am able to live a full and busy life. I am a full time carer for my husband as he is very ill with heart failure and arthritis and many other illnesses. I have to do all the driving and many other jobs around the house. For relaxation I have my sleep every afternoon and go line dancing two nights a week. My friends at the dancing say I seem to enjoy the fast dances the most but they didn't know me when I was unable to walk.

Vera Jones, Skelmersdale, Lancs

(Ed. Oops. I thing Gravis objects to the term 'Sufferer' as well. Over to you guys for your views)

Dear MGA,

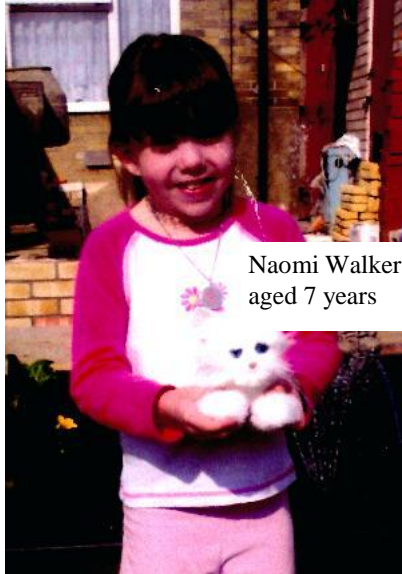
We have enclosed a cheque for £110 which was raised through our Fund Raising Book at Christmas. We had help from our family and friends and of course ourselves to raise this amount. We know how important it is to raise money for research as our daughter Naomi has Congenital Myasthenia Gravis and have also lost another daughter with it as well but that was before Naomi was born. We have your magazines which we find very useful

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and interesting reading. Last year through the research team they managed to find our daughter's faulty gene, although this make no difference to the care and treatment she still needs, it is still essential to carry on the research that is needed. Who knows, one day they might find a cure. It took over 6 years to find her faulty gene. It is not the chemical between the nerve and the muscles which we understood it to be, but it is that she has not got enough receptors.

Thank you for your continuing support.
Yours faithfully,
Ron and Jayne Walker,
Stowmarket, Suffolk

(Ed. Thank you very much. It is most gratifying when people understand the link between MGA's fundraising and research. Without one, the other would be much reduced)



Naomi Walker
aged 7 years

Hi, It's Danielle Angus again! I still have my MG but it is a lot better. I have had my thymectomy. It was a success and my thymus gland was about five times larger than it should have been. I was in hospital for two weeks and when I was in intensive care I became really ill and had to have some of the immunoglobins which made me a bit better. I am really glad I had the operation because when I went into hospital my breathing was 70% below normal and I could barely walk. Now I am slowly getting better and I have just started taking steroids (Prednisolone). I'm only on half a tablet (.25 mg) and they are already showing some affect. I'm also on 30 mgs of pyridostigmine and sometimes that dose seems too much.

A week after I came out of hospital, I went back to school for half days. They made me a special card about my illness so I can show the teachers. I had problems with some of them before the card was made. I am really desperate to be normal again and I'm still in shock. Words cannot explain how hard it is for me when I see people smiling and running around. I cannot even laugh sometimes and I feel like a freak when people make fun of my speech. It makes me sooo angry. I will be taking

special counselling to help me speak. I get angry when people don't understand what I am saying and that causes me more stress. Sadly, it might be a year before I'm hopefully normal. I really want to start running again. I have written this to update and thank you for putting my last email in your newsletter.

Danielle Angus
Via email

Dear Editor,
Back in 1998 I wrote to the local branch of Sainsbury's and asked if we could be put on their list for the Penny Back Scheme. This encourages customers to re-use their carrier bags to reduce waste and help the environment. For each bag re-used, the customer is given 1p back and can then either keep the 1p or place it in a charity box. After about 3 months this money is then sent to the charity. I was told I would be put on their waiting list but it might take 12-18 months. I had forgotten about this, but in October 2002 they contacted me and said that MGA would be on the Scheme in their York Branch for 3 month commencing 7th Oct. I got an even bigger surprise when in January I received a cheque for £418.51p for MGA. I thought this was marvellous and well worth the wait. So, if there are any MGA Branches that feel like writing to their local Sainsbury's then don't give up hope if it doesn't come off for a while. They don't forget about you.

Margaret King, Chair, York Branch MGA

Dear Sir,
I wrote an article for your magazine recently on Dr. Mary Walker and myasthenia gravis. I also maintain a web site for Dr. Walker, the address of which has changed. The new address is:

http://www.members.aol.com/jdjandsje2/dr_mary_walker/index.htm

Yours sincerely

JD Johnston,
Dept of Biochemistry & Haematology
Queen Elizabeth Hospital, London

Dear Editor,
I am a sufferer of Congenital Myasthenic syndrome with slow channel syndrome. I have children with this condition also, and I would like to hear from anyone else who has the condition and how it affects their life. My web page is: <http://myweb.tiscali.co.uk/myasthenicsyndrome/>

Many thanks,
Richard Payne

Email: myasthenicsyndrome@tiscali.co.uk
ICQ No. 203399398

Dear Ladies and Gentlemen
Re: MG in Kazhakstan

I thank you very much for your quick reply. I was really impressed of the efficiency of your organization. I was sure that it might be difficult to get specific information about the medical treatment of MG in Kazhakstan. Furthermore I appreciate your efforts. For your information you might be interesting to know that I meanwhile got a reply from the Swiss asylum authorities. They contacted IOM (International Organization of Migration) and got the following answer:

"Such patients are treated free of charge and they receive all prescribed drugs for free, including Mestinon. The officials confirmed that the West Kazakhstan oblast never had problems with supplies with such medicine, but Imurek was in shortage for last 4 to 6 months, but now they have it in stock, and this drug is distributed in accordance with prescription for free as well. There is a special list of patients with Myasthenia in each oblast health committee, and in accordance with the so called "prikaz *24" (order number 24 of the Ministry of Health), this category of patients have to receive all prescribed medicines for free like patients of Diabetes mellitus.

With my best regards
Isabelle Müller
Legal Office of Caritas Switzerland
(*Ed, we are very pleased to have been of help*)

Dear Editor,
I was diagnosed with MG in May 2001 and have at last found a book on the Amazon website (www.amazon.co.uk) dedicated to living with and the treatment of MG which may be of interest to readers of your newsletter. It is called *Attacking Myasthenia Gravis* by Ronald Henderson, an American Doctor forced into early retirement due to MG. It costs £20 approx and covers symptoms, treatments, research and disease management and includes the experiences of three other MG sufferers. Whilst writing, I wondered if any readers could offer advice relating to early retirement on account of this condition. Anyone who suffers from MG is aware of the overwhelming fatigue and the devastating effect of encountering breathing difficulties quite apart from generalised muscle weakness, which makes daily tasks difficult or sometimes impossible - even whilst on medication. Unfortunately, due to the intermittent nature of the disease, it is difficult to present a convincing case for retirement on medical grounds. I work full time as a school bursar but I know that MG prevents me from doing the job to

the best of my ability. If you have any advice or recommendations I would be pleased to hear from you on email at leej012@medway.org.uk or perhaps you could drop a line to MGA who will send it on.

Yours sincerely
Julie Lee, Kent.

Dear Sirs,
I am uncertain if I am contacting the correct person or not, but I would very much like to be able to go onto your Pen Friends list. I live in New Zealand and I am 66 years old. I have had MG for about 9 years including a very long stay in hospital on a respirator for 18 weeks, then a lengthy stay so that I was in hospital for a total of eight and a half months. However, I have been in remission now for six and a half years and presently feel very well. Your address was given to me by my daughter who happened to pass along a corridor at the John Radcliffe Hospital where she is nursing and you were having a conference.
Yours faithfully,
Esme McMillan
(Email from bobsme@xtra.co.nz)

Dear Karen (*RO for Ireland*),
May I wish you well in your valuable work for MG. Sadly I have to inform you that Mrs Renee Cooper died recently, she was a lifetime honorary member of MGA and held the aims of the society very close to her heart.
Best Wishes
James Cooper
(*Ed, please accept our condolences at this very sad time, both for yourself and Renee's family and friends.*)

Now, that's interesting...

A new Website aims to tackle Mobility Con Merchants and Rip Off Cheats - head over to www.mobilityripoff.co.uk for the full story.

The Patients Association sends out a newsletter by email. If you would like to subscribe, then log on to www.patients-association.com

Support for families with disabled children can be found at www.cafamily.org.uk

The MGA Information Pack

The Publications Sub-Committee is working on an Information pack consisting of six Volumes; these will draw together and update previous MGA leaflets and publications. I am pleased to be able to say that we have now completed Volume 1, '*A Medical Guide for Patients with Myasthenia Gravis*'. We have also produced a booklet '*Facts about MG for Patients and Families*', designed to inform newly diagnosed patients and their families; and a recruiting leaflet '*Volunteering to help the MGA*'.

By the time that you read this, a copy of each should have gone out to all Branches and ROs. Further copies are available, free of charge from Keynes House, although a donation towards the cost of post and packing is always welcome.

The titles in the Information Pack series are:

Volume 1 - A Medical Guide for Patients with Myasthenia Gravis: Medical Information on Myasthenia Gravis for those people who have been diagnosed with the condition.

Volume 2 - A Medical Guide for Patients with LEMS or Congenital Myasthenia: Medical Information on LEMS and Congenital Myasthenia for those people who have been diagnosed with these conditions.

Volume 3 - Additional Information for Myasthenic Patients: Information on complementary treatments.

Volume 4 - General Information for Myasthenic Patients: Information of general assistance to people with myasthenia, including Driving and the DLA, the DSS, prescription charges, insurance and other helpful organisations and Charities.

Volume 5 - Medical Information (Medical Professionals): Information for medical and allied professionals. Details of Myasthenia Gravis, LEMS and Congenital Myasthenia with a greater emphasis on the neurological effects and drug information.

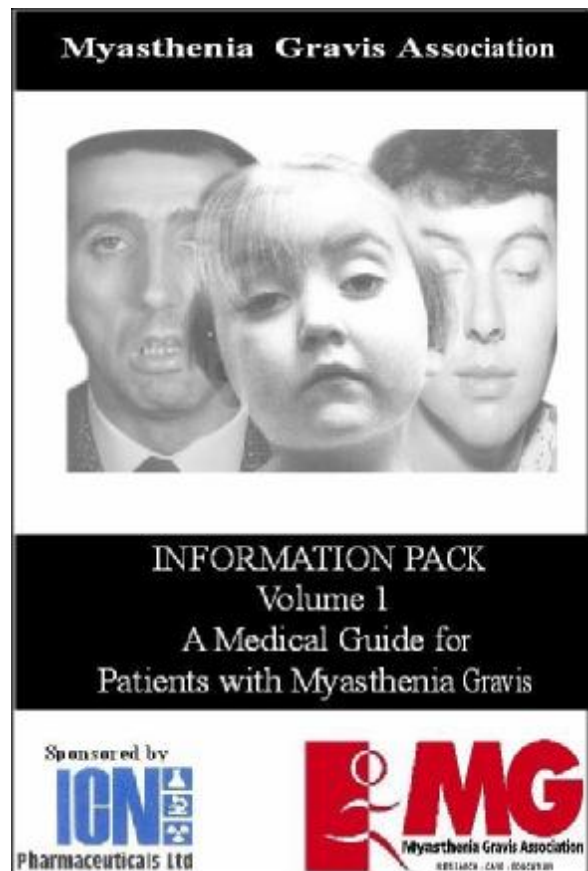
Volume 6 - Medical Articles: Extracts from medical articles published in the MGA Newsletters.

As each is volume published, details will appear in the MGA News and a copy will be sent to Branches. **To help the office staff, please do not try to order a Volume before it has been published. You will be notified via MGA News.**

I gratefully thank all our good friends who are helping to compile the medical volumes. These include our President, Professor John Newsom-Davis, Professor Nick Willcox, Dr Ian Hart, Dr David Hilton-Jones, Dr David Shlugman, Dr Ian Spreadbury and Dr Maria Farrugia. Many thanks also to all the back-room helpers at Keynes House and elsewhere.

Deciding what goes into the medical volumes is relatively straightforward, but what would you suggest should be in Volumes 3 and 4? If you have found a complementary treatment, a service or source of information useful, or have handy hints on living with MG, then please write to me care of Keynes House, giving full details and we will do our best to include it.

Rodney Haverson
Chairman Publications Sub-Committee.





LIFE WITH GRAVIS

Summer, or what passes for an English summer is here and gardening is in full swing. At least it would be if all my get up and go hadn't

got up and went. When Mrs Gravis and I moved here, more years ago than either of us will admit to, we bought the bungalow because of the large garden. After all we were fit, active and had two large German Shepherd Dogs which we trained and entered in obedience competitions. Then MG began its insidious course, and I began to get tired and unable to do all the things I had been doing. I loved my garden and my dogs, "there must be a way round it," I thought.

There was, I would use my 'flair' for gadgets and bargains. Mrs. Gravis will tell you that our loft is stuffed with them, most of them were 'mail order', and "none of them worked", she would say. I will admit that there are some dodos, but not all were failures. The first useful thing that I found was a gardener's working seat. This takes the form of a toolbox on wheels with a seat on top. Best of all it was half price in our local DIY store's sale. Using it I can move along beside a bed without having to get up and down each time that I need to move. Special long handle trowels and forks etc mean that I can reach into the middle of the beds. The one down side is that our garden is on the side of a valley. There is nowhere dead level and if I don't put a chock under the wheels, I can find myself taking off down the garden towards the very prickly Holly hedge at the bottom of the slope.

Like a lot of Myasthenics, I find that repetitive actions range from tiring to impossible. This makes trimming the hedges difficult. Thankfully, a good friend does the main hedges for me, but I have found that I can manage lightweight, rechargeable, battery driven garden clippers. I sit on my gardener's working seat and quietly trim the box hedges round the herb garden. It is also good for trimming the lavender and Mrs. Gravis is all in favour of this, lavender being a calming herb. She says I am much more manageable after doing the lavender.

I was amazed at the range of lightweight, modified

or battery driven tools which enable the less able gardener to cope. I have spent many happy hours cruising garden centres and DIY stores in my faithful wheel chair looking for these items, closely followed by Mrs Gravis intent on curbing my urge to buy the less practical gadgets.

I find that small maintenance jobs can be carried out comfortably using a Workmate type bench, a stool and a Mrs Gravis to fetch and carry the essentials. That, of course, includes tea and Coffee. I suppose that the prime tool for this area of endeavour is my rechargeable electric screwdriver, which will also take small box spanner heads. Admittedly the battery makes it heavier than I would like, but I can still get more screws in or out before getting too tired than I could with a manual one. I don't attempt these types of jobs on myasthenic days when inanimate objects such as nuts and bolts take on a life of their own and fly out of my hands without warning.

It's not just in the garden where gadgets help. I find that at times, bending or crouching down to pick things up from the floor is impossible. If I can get down without falling over, I then have to shout for Mrs Gravis to help hoist me up. Getting me up again is no mean feat let me tell you. To cope with picking things up off the floor I have a 'helping hand', a disabled version of the tool you see park keepers using to pick up litter. No not the spike, the other one. With a bit of practice It really is amazing what you can get hold of with it. I can even get books down from our higher bookshelves with it.

My latest handy gadgets have solved a long-standing problem. I am always dropping things and this includes my walking stick. This usually happens in a shop, or when it will cause Mrs Gravis most annoyance and embarrassment. The answer has been a 'Walking Stick Wrist Strap' and a 'Walking Stick Holder'. The strap anchors the

MGA EVENTS ON THE WEB

If you are one of those people who actively enjoys taking part in our (sometimes adventurous) FUNdraising events, why not visit our Events Website regularly. Go to www.mgauk.org.uk and then click on the Fundraising button shown in the Menu Box on the left of the screen

(Continued from page 10)

stick to my wrist, so that if I let go it doesn't fall. The holder is a cunningly designed clip-on device, which allows me to hang the stick on a tabletop or counter. Its especially handy in places like the Post Office when you need both hands and can lean on the counter.

Of course all of this activity is only possible on a good day, on bad days I use that other handy gadget, my reclining chair. Here, before nodding off, I dream of the next essential gadget I need. Well, a new catalogue has just plopped through the front door and that next wonder may just be in it. So before Mrs Gravis can intercept and destroy it, I am off with my 'Helping Hand' to retrieve it.

May 2003

The 'Walking Stick Wrist Strap' and 'Walking Stick Holder' are available, mail order from GPSP, telephone 01275 842322.

All other items are in most big garden centres, DIY stores or Disabled living shops.

(Continued from page 5)

biotic (the first of a group of antibiotics called *ketolides*).

There have been several reports of it worsening myasthenia, including one fatal case. Obviously, its use should be avoided in all patients with myasthenia wherever one can. Just possibly, however, it may be the only antibiotic to which a resistant infection is sensitive. In such an unusual case, the drug will have to be used, but with extremely close monitoring of the patient for any downturn, particularly in the breathing muscles.

Madonna Hits the Town for MGA

Ex Coventry/Warwickshire Branch Chairman, Fiona Ruddick has a secret up her sleeve. In her 'spare time' she does a Tribute to Madonna. This is something she has been working on for some time. And, let me tell you, the rumour is that she is BRILLIANT. Not only does she sound like Madonna, but she actually looks like her too. Fiona has agreed to do a Madonna Tribute night at JCB's Lakeside Club in Stafford on the 28th November 2003. Tickets (£5) are available from ex RO, now Chairman of the Staffordshire North Branch, Diane Smalley. You can contact her on 01889 564789 for tickets for this very special one-off performance.

NOT TO BE MISSED.

Veteran Actor Karl Malden (91 - star of Streets of San Francisco) is fighting myasthenia gravis, so reports the Daily Mail on 16th April 2003. He said "The disease first affected my left eye. For several months I couldn't see unless I put my finger on the lid and lifted it up. Then I tried an amazing experimental procedure where a spring-like device is inserted to hold the eyelid open. I've had both eyes fixed. Now I can see and wink and blink."

Norman and Joyce Blades wrote in from South East London, Branch to notify us of the sad death of Mrs Dorothy Pope of Orpington. Dorothy was diagnosed with MG when she was well into retirement and had little help with understanding the disease until she chanced upon a notice about a branch meeting who then put her in touch with MGA. She could not always attend branch meetings but went to as many as she was able to and she appreciated being able to talk to people who understood MG. Her family and friends showed their affection and respect for Dorothy by making donations to MGA of £458. We echo Norman and Joyce's sentiments, in sending our deepest sympathies to the family and friends of Dorothy.



Edition	Copy Needed
Autumn 2003	8 Aug 2003
Winter 2003	7 Nov 2003
Spring 2004	14 Feb 2004
Summer 2004	14 May 2004

Please submit articles and photographs well before copy deadline date where possible. Edition

deadlines are for guidance only. The Printer's resources often dictate the actual deadline. Please endorse the reverse of each photograph with a caption and date and include names and locations. If you wish photos returned please indicate on the reverse and give the address. However, there are **NO guarantees!** as they pass out of our hands during publication. Published articles/letters may be shortened and/or changed to accommodate available space.



Region 8 - Steve Annable Tel: 01457 766410 Email: steve@mgauk-region-8.org.uk

Lancashire Branch's Craig Priestley with his school, Ashton upon Ribble High in Preston

staged a music marathon. Various activities are expected to raise over £1,000 by July. Craig is pictured on the right along with **Joan & Terry Jump** from the branch. **North Manchester Branch** have a new Treasurer in **Alan Binns** from Blackley, and **Scott Wilson** raised over £400 with a parachute jump for the group.

Bolton's Community Leaving Chest are to fund the **Lancashire Regional Conference** on Sat 11 October at the Holiday Inn, Bolton. **Dr Jon Sussman** will be guest medical speaker, **North Manchester Branch** will host the conference.

Medical Videos have been supplied to all GPs and Opticians in Cumbria to help improve diagnosis and Health for Bolton are to fund for the Bolton area as well.

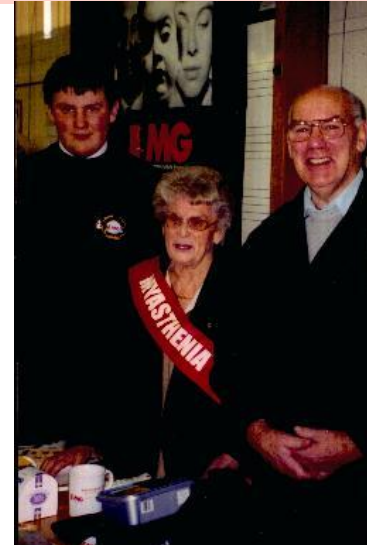
South Yorkshire Branch have a new website thanks to **Barry Gregory** – why not take a look – www.mgsouthyorks.org. **Terry Hulme, Ken Poole** and **Keith Bennett** were all re-elected as officers for the Branch at their AGM in April.

South Yorkshire Branch will host this years **Regional Conference for Yorkshire** in Doncaster on Saturday 25th August – watch this space!

New Regional MG Clinic – Dr Jon Sussman and Dr Mark Roberts are to run a new monthly clinic at Hope Hospital, Salford to provide a setting for managing patients with difficulties, as well as further research following a successful new drug trial. Patients with MG can be referred there for one off assessments of difficult problems or for continuing neurological care.

Wigan had £100 donation from local Rotary Club thanks to chair **Ralph Morris**. **Leeds Branch** together with **Brighouse and York** are planning a sponsored walk at Harewood House – call Heather for details on 0113 2502816. **Brighouse Charity Dinner** is now Sat 20 Sept – call Dorothy for details on 01484 714230.

(Continued on page 13)



STOP PRESS... A new Branch for Huddersfield

was opened in April thanks to George Parsisson who will act as Chair, Susan Johnson-Secretary and Paula Milburn as Treasurer. For more details call Sue on 01484 686719



An Abseil at Leeds Armouries in April raised over £1000 for Yorkshire groups.

Picture shows the York team-Heather and Darren King plus Steve and Marc Dawson together with Steve Annable RO for Yorkshire who also completed the Abseil.



Calling all Football Fans

Steve has made contact with a BBC Sports Reporter called

John Richardson who produced a book with Eric Harrison which became a best seller. Eric was a subject of This Is Your Life and was a famous scout for Manchester United. He also discovered the famous class of '92 (Beckham, Scholes, Giggs, the Nevilles, Butt, etc). The book, entitled, "The View From The Dugout" sells for £8.95 and £3 goes to MGA. If you are a Man U fan, or even a Football Fan, then the insights into football that this autobiography gives are not to be missed. Eric will even personalise the book for you at no extra costs. *If this is something you are interested in, please give Steve a call (details at top of page).*



Region 4 - Louise Durnan Tel: 0141 5784233 Email: louise@mgauk-region-4.org.uk

25th Birthday of North of Scotland Branch



The North of Scotland Branch is celebrating its 25th Birthday on 18th June this year. Margaret Lamb, the Chairman, and Margaret McPherson, the Secretary, started the branch in 1978 and have been committee members since its inception. The ladies have dedicated much of their time in raising money and awareness of MG. The

branch has raised over £67,000 since they first began 25 years ago.

On behalf of the MGA, we would like to thank the North of Scotland Branch and its members for all their hard work over the years and long may it continue.



The Glasgow & South Branch received a very generous donation from the Robert Burns Masonic Lodge for £5275. We would like to thank the Lodge and Mr Huxtable, who is a member of the MGA and who nominated the charity, for their very kind donation. Pictured above are some members of the Lodge, Jim Huxtable, Alec Mulholland and in the centre, our very own, Louise Durnan.



In February 2003 17-year-old Lindsay Hyndman, raised over £750 for her skydive and also had a few articles in her local paper to help raise the awareness of MG. Also, well done to Scott Hodson, Gerald Shovlin & Craig Smith for doing the Skydive. On 6th April, over £1500 was raised from the abseil from the Finnieston Crane, Glasgow – the tallest crane in Scotland! Congratulations to all those who took part!

(Continued from page 12)

Warrington Awareness Day is Sunday 13th July – can you help run a stall for an hour or two – call Chris on 01928 787231 for details.

Dear Steve, I was working for the last three weeks at the Crucible in Sheffield on the Embassy World Snooker. Through my BBC floor manager friend I have obtained a programme of the event signed by many of the competitors including all the second round finalists, the BBC team of Hazel Irvine,

Steve Davis & John Parrott. In addition I managed to get Prince Nazeem Ahmed, and the famous Cliff (147) Thorburn. There are some 25 autographs in all, and I am sure it will be a desirable item for collectors. I wondered if we could use it to raise funds by an auction or other means at a charity event. Perhaps you could let me know your thoughts. Barry

If any body is interested in bidding for this, please contact Steve (Details top P12).



Region 13 - Rita Goldthorp Tel: 01980 626062 Email: rita@mgauk-region-13.org.uk

The Swansea and South Wales branches have both been very busy organising the Awareness Day at the Welsh Assembly on June 18th. The Morgan Crucible Trust has made a donation towards the cost of information packs. The winner of the quiz organised by Fred and Sheila Gray was A. Taylor from Morrision. The Swansea branch would like to thank everyone who took part and raised a grand total of £384. Special thanks to Keith Thomas who was instrumental in providing the prize of a long weekend at the Diplomat Hotel in Llanelli. The South Wales branch have organised Awareness and collection events in Asda Blackwood and the University Hospital of Wales. Both events have been successful for the sale of balloon tickets.

The Southwest

Our newest branch in the Southwest, The South Devon branch, have had a very successful week-long collection at Marks and Spencer in Torquay which raised a fantastic sum of £1,028. Well done to all concerned. Several collections are planned in the Southwest for the coming months including Honiton and Dunster shows and the Taunton flower show. Donations of items to sell would be appreciated – ring Rita if you have anything. The new Yeovil and District Branch have received a donation of £100 towards the cost of holding meetings in West Dorset, and people in North Devon who meet regularly in Barnstaple have received a £100 boost to help with the cost of their meetings.

Treks and Bike Rides continue to receive a lot of enquiries. This new form of raising funds for MGA has proven to be very popular with people who know nothing about the illness but just want to do the fun events on offer. With this in mind we are extending our range of events for 2004 and hope to include a cycle tour of the Danube, cycling for softies in Jersey and an adventure weekend in the Brecon Beacons. We have also delayed our Morocco trek to April 2004 so it's not too late to book your place. Details for any of the above from Rita.



There are 3 new branches in the Southwest, Yeovil and District catering for people in the South Somerset and West Dorset area where we welcome Ann Dean, John Mason and Jane Goodchild (Picture above with RO, Rita Goldthorp), East Devon and Exeter where we welcome Caroline, Mary and Duncan and South Devon where we welcome Clive, Irene and Judy. If you would like details of their meetings, or the informal meetings being held in North Devon and Cornwall then please contact Rita.

We are delighted to welcome Diane Williamson and Alex Tunstall as new committee members of the Devon and Cornwall branch based in Plymouth.

For health reasons, the Chair of Swansea and District, Eira Gape has had to step down. We would like to take this opportunity of thanking her for all her hard work. Eira says that she will continue to work with the branch but needs to take a break from the committee.

Chat List

Only 1 name put forward so far:-
Marilyn Walker, Carlisle area 01228 541535

If you enjoy chatting to people and would like to be included in this list, please contact us with your details. The Chat List will be printed from time to time in this Newsletter and will show :-

*Your: First Name(s), Tel No. Geographical Area.
Any specific topics/areas of chat.*

People who join Chat List should expect to receive calls from other people who may wish to talk about specific MG matters or may just want somebody to talk to. When we publish the Chat List we will remind people that they need to ask if it is convenient to talk at that time and that Chat List members are volunteers and their rights and privacy must be respected.

The London Flora Light is a really fun way to get some exercise and raise funds for your local branch or MGA nationally. The 5km (3mile) course is all on the level around Hyde Park London, and this year for the first time around the Bullring in Birmingham.

At the end of the event each person is given a 'goody bag' full of lovely useful things to take home. We can supply application forms and sponsor forms – just contact Rita (p14)

If 5km is just too tame for you, then consider one of our treks or bike rides. We had to delay our Morocco trek because of the war and this will now go in April 2004. Quiet and peaceful starry nights, friendly people and good clean fresh air are all on offer in Morocco – ask Rita for further information.

Money is available for our work if you know where to look for it! Our new South Devon branch managed to get a one week collection in the foyer of their local Marks and Spencer store and raise the fantastic sum of £1,028. Yeovil and District had a one day collection at Sainsbury's in Sherborne and raised £132 - well done to all concerned. August will be an exceptionally busy month for Southwest branches with representation being made at Honiton and Dunster Shows, The Taunton Flower Show, Awareness at The Mall Cribbs Causeway and a special Craft Fayre in

Padstow. If you would like to be involved or if you have items to donate for sale then please contact Rita. Trust applications are always welcome and we are delighted to have received £100 from the Digby Trust to help fund the work of Yeovil and District and £100 from the Well-spring Charity to help fund work in North Devon.

Judy Edwards shown here outside M&S. Together the South Devon Branch raised over £1,000 for MGA



NEW YEAR GRAND LOTTERY DRAW 2003

The Lucky Winners of this years New Year Grand Lottery Draw 2003 are:

Mrs JH Nunn, Bishopsteighton, Devon, who wins

£1,000

(and kindly donated £250 back to MGA)

Mrs C Todd, Eastham, Wirral, who wins

£250

Mrs J Winter, Crowborough, E. Sussex, who wins

£100

And **TWO Runner Up Prizes** go to

Ms S Wise, Sale, Manchester.

Mr T Phelan, Headingly, Oxford

HEATH LAMBERT

Our relationship with Heath Lambert is now firmly established and many members have benefited from this partnership. They already have in place household, buildings and contents cover, motor, pet and caravan in the general insurance sector. Life cover quotes are available and their dedicated team who understand living with MG, will be pleased to take individual details to determine if terms can be obtained. They can now, also offer travel insurance, details below.

Travel Insurance Offer from HLAP

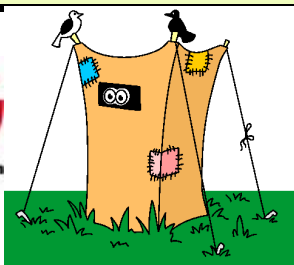
We are able to offer an Annual Travel Insurance arrangement with a wide range of benefits including Cancellation and Curtailment, Medical and Other Expenses, Money, Baggage, Personal Liability, Personal Accident, Travel Delay etc. We are also able to offer a highly competitive

Single Trip product with a comparable range of attractive benefits. Winter sports can be included under both options.

As with all our products HLAP will operate the Travel insurance from their Norwich office, which will provide dedicated staff to handle any sales quotations, administration calls and advice on the product. Please call for an immediate quotation. A member of the team will be happy to assist you with your enquiry.

Every policy arranged by HLAP will result in a commission payment being made directly to the MG Association.

HLAP can be contacted on 01603 828359



Don't Hide Support Your Charity

Research Care Education

Please quote our
FULL Address,
including our name
in all correspondence
As shown below

This address is shared with
other companies, so please
include the full address as
shown including our name.

Myasthenia Gravis Association
Keynes House, Chester Park
Alfreton Road
Derby DE21 4AS

Tel: 01332 290219
Fax: 01332 293641
Email:
mg@mgauk.org.uk
Website: www.mgauk.org.uk
Registered Charity:
No. 1046443

We're on the WEB
www.mgauk.org.uk

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200 CLUB WINNERS

Draw Feb2003

1st Mr & Mrs Hogarth, Bournemouth £60
2nd MK Lingard, Burscough, Lancs £30
3rd Mrs B Gorrell, Preston, Lancs£15

Draw Mar 2003

1st Mr R McPherson, Stonehaven, Abdns £60
2nd Ms A Carlyle, Cirencester, Glos £30
3rd Mrs R Scott, Tullibody, Alloa £15

Draw Apr 2003

1st BW Durrant, Norwich £60
2nd Mrs SW Huggett, Betchworth £30
3rd Ann Wheelhouse, Halesowen, W.Mids £15

PLEASE APPLY/RE-APPLY FOR MEMBERSHIP TO HELP MGA

To apply OR Re-Apply for membership of the 200 Club, please complete and return the form
to the address shown below.

This is an easy way to raise funds for MGA with the chance of winning a prize into the
bargain. Club members pay £1 per month (£12 per year) with half the proceeds going to fund
research, care and education. The other half is given out as prizes to members.

NB. Please enclose a stamped addressed envelope with your application and send to:-

Mrs Margaret McPherson
4 Martin Place, STONEHAVEN,
Aberdeenshire, AB39 2LG

Enquiries to 01569 760475

PLEASE ENROL ME AS A MEMBER OF THE 200 CLUB FROM AUGUST 2003

Name: _____ Address: _____

I will pay by: 1. Monthly Cheque/Postal Order (Payable MGA) []
2. Full remittance of £12 enclosed []
3. Bankers Order (please completed below) []
(Please tick one box only)

BANKERS ORDER

The Manager (full bank address please)

Sort Code _____ Account No. _____ Account Name _____

Please pay to Myasthenia Gravis Association, Account No. 61214950, Sort Code 40-33-30,
HSBC, 15 Uttometer Road, Mickleover, Derby DE3 5DA, the sum of £1 per month for 12
months commencing on 1st August 2003.