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## A New Patron for MGA

The Myasthenia Gravis Association is delighted to announce that **Ed 'Stewpot' Stewart** is to become one of the charity's patrons alongside Nick Ross.

Ed's career in radio goes back to the 1960's, when after working in Hong Kong, he joined the 'Pirates' at Radio London before moving to the BBC. Known to many from the TV programme,



*Crackerjack*, he now has a weekly programme on Radio 2 on Sunday evenings. He fills his weekdays working on a Spanish ex-pat radio programme. Ed's passion is golf, but for the last two years he has been busy writing his autobiography *Out of the Stewpot*.



## A Brainstorming Consultation

Representatives of MGA (above) got their heads together in a collective brainstorming session. Mr. Geoff O'Donoghue (right) performed the excellent and difficult task of co-ordinating, directing and controlling the day. The full story of this session which was held in Derby in March can be found inside this edition.



Sponsor for MGA's Publications and Literature

## Message from the MGA Chairman

In March the Trustees hosted a 'Brainstorming' session to help us focus our minds on ideas priorities for the future development of the MGA. We are grateful for the time and effort put in by the staff and members who attended. You can find a full account (by your Trustee, Professor Nick Willcox) on page 4 of this issue. A lot of very useful material came out of this meeting, and we are now in the process of sifting and prioritising it for study and possible action.

The first action we have taken as a result of the 'brainstorming' session is to simplify the membership scheme of MGA. The grades of Associate Member and Junior Member of MGA will cease to exist. Associate Members will be given a choice of either changing to Full Membership - or giving up their membership (which will not stop them accessing all the services and activities of the MGA). This choice, which will affect about 300 Associate Members, will be available when the Associate Membership next becomes due for renewal. If an Associate Member wishes to become a Full Member before the end of their Associate Membership, they should contact our support staff at Derby.

Becoming a Full Member confers the right to vote at General Meetings of the

Association. I strongly urge all Associate Members to become Full Members. The abolition of Junior Membership will have no practical effect since the current grade of Junior Member confers no advantages on the member. These changes will have little effect on the operation of Branches of MGA since all Branch Officers already have to be Full Members of MGA.

On a separate note, I am sorry to have to inform you that Mr Malcolm Palmer has resigned from his position as a Trustee and Director of MGA. Malcolm had been on the Board for a little over a year; in that time he impressed all of us, both with his breadth of knowledge and experience, and his commitment to the welfare of myasthenics. He will be sorely missed by the other Trustees. Thank you Malcolm.

Finally, I would like to thank our CEO and staff at Derby for the efficient way they handled the move of our Head Office to its new premises. The new offices are a great improvement. As well as providing a much better working environment for the staff, they allow us to comply fully with the requirements of the recent disability employment legislation - which would not have been possible in the old office. The move was accomplished with hardly any interruption to our activities, thanks to the hard work of all the staff at Derby.

PETER FINNEY *Chairman of the MGA Board*

## An Update from Alasdair Nimmo (CEO)

Hello everyone,

Welcome to this edition of your MGA News. I hope you find it useful and informative. I am really pleased to let you know that we have now completed the up-dating of our existing medical video which has now been produced in CD ROM format. It is available from the MGA Head Office (free but if you could manage a contribution to help cover costs, it would be appreciated). The CD ROM comprises an Introduction and four

videoed talks about Myasthenia Gravis, LEMS and Congenital Myasthenia. It is designed to give basic information about the diseases and their treatment, in an understandable form for newly diagnosed myasthenics, their families and their carers. This CD ROM will also be used as a tool to help educate medical professionals. It replaces the previous video which was available on VHS cassette. Our sincere thanks to those of you who gave us their support: Professor John Newsom-Davis, Dr. David Hilton-Jones, Professor Nick Willcox, and our sponsors, Valeant Pharmaceuticals Ltd.

I know I keep banging away, but thanks to you we are raising awareness with MPs so please continue to rally round and lobby your MP. Write, call or send the enclosed postcard to them. Or go online at [www.mgawk.org.uk](http://www.mgawk.org.uk) and follow the link "Lobby your MP".

Our campaign continues to gain momentum. Don't forget we are looking to hopefully gain support of the following:

Question to Prime Minister or Leader of the House To ask the Prime Minister or Leader of the House if he/she will make a statement on the disease Myasthenia Gravis and how the government can support those who are diagnosed with Myasthenia Gravis.

To ask Secretary of State for Health by written letter

If he/she will make a statement on Government support for those who are diagnosed with Myasthenia Gravis and their families.  
If he/she will make a statement on hospital waiting times for patients diagnosed with Myasthenia Gravis.

What plans does he/she have to raise the numbers of consultants and nurses qualified to diagnose and treat Myasthenia Gravis.  
What plans does he/she have to increase awareness about Myasthenia Gravis amongst the medical profession?

If he/she will make a statement on Blue Badge entitlement for those diagnosed with Myasthenia Gravis.

To ask the Secretary of State for Works and Pensions if he/she will make a

statement on benefit entitlement for those diagnosed with Myasthenia Gravis.

So please support us by canvassing your MP and continue to send us their response as we will follow these up with the MPs concerned. The more MPs we have supporting us the stronger our case.

In case you were not aware, your team in Derby Support has moved into other premises located in Derby. This move allows us to comply with current legislation ensuring that those with disabilities can gain access to our offices. The new address is on the back page of this and future editions.

Thank you.

ALASDAIR NIMMO CEO



*We are located on the First Floor (above the van).*

*Our full address and contact details are shown on the back page of this edition.*

## Obituary

We are sorry to have to inform you of the death of one of our members, Mr. William Scott who passed away on 12th April 2005 at the age of 76. William was for many years a very active member of the Glasgow Branch. He will be sadly missed by the entire group. Our sincere condolences go to his wife, Rachael and family.

## MGA Brainstorming Session March 18th 2005

### Background:

The Trustees felt that we needed to take a fresh look at MGA's goals and how we can achieve them. To this end, we assembled a team comprising 3 subgroups – 6 Branch Members, 5 Staff and 7 Trustees. We also recruited a really excellent facilitator, Mr. Geoff O'Donoghue, to ensure the day went well and stayed focused. We are grateful for all the advance planning, and for the anonymous donations we received for this venture (which more than paid for the facilitator).

We hope those who weren't invited won't feel offended; such Discussion Groups **only** work well if they are kept **small**.

### The Meeting:

The overall objectives were to:

- a. Review MGA's goals and priorities;
- b. See how far we had gone in achieving these;
- c. See what and where we needed to do better;
- d. Identify any new priorities;
- e. Plan how best to achieve them.

First of all we broke into three subgroups to discuss questions a. to c. above. They all broadly agreed on these major goals:

- **Providing support** for MG Patients and their families
- **Increasing awareness of MG and the MGA** to:
  - Myasthenics and their supporters.
  - The general public.
  - The medical and paramedical professions.
  - The NHS, politicians and the media.
- **Maintain sound finances, structures and communications** (and in Branches and Derby), which are essential for all of our activities.

### What priority is to be given to research?

While we all backed the MGA's principal missions – Research, Care and Education – Research by itself did not come at the top of anybody's list. Because even one project is so expensive (around £50,000 per year for 2 – 3 years), the MGA can rarely afford to make a big difference to existing funding from elsewhere.

**Policy options:** Some felt that MGA should focus its contributions towards special MG centres, whether in Liverpool (Walton Centre), Oxford or elsewhere. In Oxford, MGA's "Research Sister" actually spends most of her time on **Care**, providing crucial support for many patients and neurologists as well as a vital link for the Researchers (see MGA News Spring and Christmas 2004).

### *Excellent News*

***The MDC has recently announced renewed funding for both the Research Sister post and a new Research Registrar.***

Another particularly valuable bonus is the funding for Neurology Research Registrars. They spend about 3 years doing good research, usually in the lab (about 3/4 of their time). At the same time, they also get clinical training in treating myasthenics (about 1/4). This is a 'double-benefit' for the MG community, because, by the time the Registrars become Consultants, usually in other Centres, they have also become valuable experts who spread the gospel around the country.

**Things we're doing OK** – but still with plenty of room for improvement:

1. **Creating awareness.** We are already punching above our weight, and are now targeting politicians and Government policies/funding.
2. **Education.** MGA News, websites, literature, conferences all ongoing beneficial activities.

3. **MGA's Organisation.** From Branches through to ROs, Derby Support and on to the Board of Trustees.

**Things we could do better:**

4. There is **uneven coverage** of the UK and Ireland, with regards to MGA Branches and ROs. Changes will depend on more funding – perhaps from Regional or National Governments.

5. **Enthusing Members** to increase their branch activities, and improve first contacts for newly diagnosed Patients.

6. **Enthusing Members and the Public** to raise funds/give donations – but how to keep up the impetus?

7. Helping patients to tap into **State benefits** and understand their entitlements. We are working on this at the moment. If any readers know of experienced Social Workers who might help, please ask them to contact us.

***Has any reader suggestions for 5-7 above?***

***If so, please write in and let us know.***

8. Getting the **NHS to play its part.** See the final paragraph with regard to the new framework being put in place.

**The Brainstorming**

After the initial thoughts outlined above, we all came together again to classify ideas under the three main areas:

**A – Fundraising, B – Branch activities** and **C – Awareness.** Then, to sift the wheat from the chaff, we were assembled into 3 mixed groups (about 2 from each of the original subgroups). Each of these then settled down to selecting six main priorities.

**The outcomes**

The meeting covered a wide range of topics, and was well-focussed on the MGA's current problems and future needs. Needless to say, there were lots of suggestions - which the Trustees have taken away and are now considering in depth. They made a start on the very next day (at the regular Board meeting),

eg; by deciding to simplify the membership scheme by giving-up Junior and Associate levels. They feel sure that this will have no adverse effect on the current membership, while saving time and costs at Derby. This change, and how it will affect existing members, is summarised in the Chairman's notes on page 2 in this edition and detailed on the reverse of the cover sheet.

Finally, on behalf of the Charity, we would like to extend a big thank you to all those who participated, some of whom travelled a long way to attend. Your collective and individual input is much appreciated.

*(Ed: please see Lynn Pitcher's letter in the Feedback Section regarding the Brain Storming Session.)*

**Other news**

The Ministry of Health has recently issued a new Framework for the ideal handling of long-term conditions. It particularly focuses on Neurological disabilities. It doesn't specifically mention MG, but we do fall absolutely within its remit. It even mentions the Charity sector. There are many fine words, but there is to be no extra money for anything. It is hard to tell how much impact it will actually have on our work and the lives of myasthenics in the UK. The Internet address for this document is rather long I am afraid. See below. Type it all in on one long word even though it is wrapped in this column:

Nevertheless, we should be able to hold the NHS to these newly-stated goals for best-practice, so it should be useful ammunition – eg; if local Trusts seem to be under-performing.

**However, we must be very careful to avoid counter-productive harassment.**

[http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT\\_ID=4105798&chk=iKIKIb](http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4105798&chk=iKIKIb)

## Winter is Coming (and Flu is not far behind)

Yes, I know this is the Summer edition of the Newsletter, but you might want to start thinking about your flu jab and maybe your pneumonia jab also. Remember to consult your doctor and make sure they know about your myasthenia. Remember also to avoid live vaccines if you suffer from MG.

Three Reasons to get your flu vaccine:

### 1. Prevents death because of the flu.

Each year as many as 4,000 people in England die because of the flu – most are 65 or older. More people die from flu than from any other vaccine-preventable disease.

### 2. Prevents severe illness.

Each year in England, up to 10,000 people aged 65 and over are admitted to hospital as a result of the flu. The virus can lead to complications such as bronchitis and pneumonia.

### 3. Protects other people.

Getting a flu vaccination yourself can help protect your family members, especially those over 65, those with chronic disease and young children.

*NB. If you are 65 years or older, suffer from asthma, diabetes, heart disease or kidney disease you can receive a free flu vaccine from your GP or nurse.*

## New 'Aimspiro' (goat serum) treatment

A few people have raised questions on this subject following a program on television. Our understanding of this treatment is as follows:

A new experimental treatment (using goat serum) is being tried for Multiple Sclerosis (MS).

Currently, reports are preliminary and the final results have not yet been published. These will then need to be confirmed in a larger, longer-term trial before it is used more widely in MS. Naturally people are now asking whether it will also work in MG.

As you may know, MG is very different from MS, eg; MG is caused by antibodies and MS mainly by (immune) cells. Even more importantly, the immuno-suppressive treatments that clearly work well in MG do NOT cause such clear improvements in MS.

Therefore, the goat serum might very well NOT have the same effects in MG.

In any case, it is much too early to say anything more definite, eg, about its safety in the long-term. It would NOT be wise to start adjusting your current treatment without much harder evidence.

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## "Come Myasthenics of the World Unite"

### Dedicated to the skills of our Neurologists

Come Myasthenics of the World unite,  
To tell All the People of our plight,  
How this Muscle Disease is hard to bear,  
Without friends and family being there.

The Rag-Doll Disease it is known to some,  
As such, let it be known to everyone  
Ocular Myasthenics with their wistful stare,  
Whose eye-muscles have locked beyond repair,  
General Myasthenics whose bodies work,  
Their cocktail of drugs they must not shirk  
Reliant on our Neurologist' decisions

To make our muscles work without inhibition.

The cause of Myasthenia is not known,  
Nor has a cure yet been found, But for the minority of us in the World, We hope funding for research will always be around.

This Myasthenic's decision to write Poetry, to tell all of our plight,  
To make known worldwide this Disease,  
To ask for help for our eventual release.

JONATHAN GOLDMAN ©2004



I was recently asked if I could remember what it felt like to be a newly diagnosed Myasthenic, a tough question as it was more than ten years ago. I suppose the thing that I remember most

vividly is the consultant saying, "Well Mr. Gravis I am afraid that your diagnosis of Myasthenia Gravis was correct, the good news is that it is eminently treatable".

I had come to the neurologist as a result of going to my GP and suggesting, after doing much research, that MG might be my problem. I suppose that this had in some ways prepared me, but his upbeat way of telling me helped no end. The fact that something could be done to give me back some control was a major boost to my morale. An additional bonus was that my local MGA Branch had just organised a mail shot to all the GPs in their area. My GP's copy had landed on his desk on the same day that I went to see him, following my visit to the Consultant. As soon as I got home I rang MGA Headquarters and was sent an information pack, not only that, but the following day the local MGA 'First Contact Member' phoned and then came to see and reassure me. She had a very positive approach to her MG and I realised that this was the only way forward; it set me on a voyage of discovery, much of which has over the years been chronicled in this column.

The voyage continues, and has been considerably enlivened by my adventures over the past six months. I have been reminded what it is like to go through a myasthenic crisis, experienced the benefits of Iv Ig treatment, revisited Physiotherapy, Speech Therapy and Diet. Please note that I say that I went through a myasthenic crisis, although I knew that I was very ill, I never had any doubt that the Neuro team would bring me through it. I remembered what the Registrar told my wife when I went into my first MG crisis in the mid 1990s, "He will get much worse before he

gets better, but he will improve and we have never lost a myasthenic this way yet".

Mrs. Gravis delights in pointing out that I am 'odd' and that I would develop anything that it is possible to have. I couldn't let this pass and so I put it to the test, I asked a consultant, "how common is a myasthenic crisis today". His answer seems to confirm Mrs. Gravis' assertion, and makes comforting reading for myasthenics in general.

Thankfully, crises are much less common nowadays due to earlier diagnosis and more effective treatments. Very few patients of the entire MG population ever require a stay in the Intensive Care Unit; at this point Mrs. Gravis goes into "I told you so" overdrive. If a crisis does occur, it is most likely to occur in the first few years after diagnosis; this happened to me, again I am unusual in that I had a second one ten years later. Crises are often triggered by something obvious – e.g. an infection or reduction in treatment; in my case it was a severe gastric infection (source unknown) that is thought to have been the start of my problems. As a result I am now even more careful to avoid contact with the sick and unwell, I also decline to kiss 'strange ladies'. Finally, modern management is such that the vast majority of patients who do go into crisis may expect to make an excellent recovery.

In the spring 2005 edition of MGA News I made mention of using a thickening powder to assist in swallowing liquids. This does mean that you have to prepare it and wait for the powder to swell. Mrs Gravis has found a ready made 'thick' milkshake. It is made by Dairy Crest Ltd and marketed under the name Frijj. The ingredients include 'modified maize starch' which is what the thickening powder is. It comes in several flavours and we have found it to be available in most of the supermarket chains. The problem is that I find them very more-ish and although they are low fat, I fear for my waist line.

## House of Commons Hansard Written Answers for 17th March 2005

### (Diagnosed of) Myasthenia Gravis

**David Taylor:** To ask the Secretary of State for Health (1) what the average waiting time is for patients diagnosed with myasthenia gravis in (a) the East Midlands and (b) England. (2) what steps he will take to increase the awareness of myasthenia gravis among NHS health professionals.

**Dr. Ladyman.** Figures on waiting times for treatment of neurological conditions are published, but myasthenia gravis is not separately identified. We have no specific plans to raise awareness of the condition among the medical profession. The Department is not responsible for setting curricula for health professional training; that is rightly the responsibility of the statutory and professional bodies. However, we do share a commitment with these bodies that all health professionals are trained so that they have the skills and knowledge to deliver a high quality health service to all groups of the population with whom they deal. The national service framework for long-term conditions focuses on improving services for people with neurological conditions. While the framework does not cover myasthenia gravis specifically, it does recommend improvements in standards, care and support that will benefit everyone with a neurological condition.

### (Benefit entitlement for people of pensionable age)

**David Taylor:** To ask the Secretary of State for Work and Pensions what the benefit entitlements are for people of pensionable age who are diagnosed suffering from myasthenia gravis.

**Maria Eagle:** I refer my hon. Friend to the reply I gave to the hon. Member for Blaby (Mr. Robathan) on 1 December 2004.

**Mr. Robathan:** To ask the Secretary of State for Work and Pensions if he will make a statement on benefit entitlement for those diagnosed with myasthenia gravis.

**Maria Eagle.** We do not pay benefits based on medical diagnosis. Incapacity benefit is intended to provide a source of income for sick and disabled people of working age who

are unable to work. Entitlement to disability living allowance is based on walking difficulties and/or the need for personal care which results from severe disability. The customer's medical condition is not, necessarily, the key factor. Rather it is the disablement that results from it and the effects of that disablement. We are ensuring that the benefit system encourages and promotes work where possible. However, we recognise that those with the most severe conditions may never be able to work, and benefits provide security for those for whom work is not an option.

### (Blue Badge Scheme) Myasthenia Gravis

**David Taylor:** To ask the Secretary of State for Transport if he will make a statement on the eligibility of sufferers of myasthenia gravis for the Blue Badge scheme.

**Charlotte Atkins:** The Blue Badge scheme is designed primarily to assist people with severe difficulty in walking, whatever the cause of their disability. People who are registered blind also qualify under the scheme. Drivers with severe disability affecting both arms may also be eligible. Local authorities, which are responsible for administering the scheme, will decide on an individual's eligibility on the basis of these criteria. People with myasthenia gravis will be eligible for a badge if they meet the criteria.

### (Medical Training) Myasthenia Gravis

**David Taylor:** To ask the Secretary of State for Health what steps he will take to increase the number of NHS (a) nurses and (b) consultants qualified to diagnose and treat Myasthenia Gravis.

**Mr. Hutton:** Post-registration training needs for the national health service staff are determined against local NHS priorities, through appraisal processes and training needs analyses informed by local delivery plans and the needs of the service. Access to training is affected by a number of factors, such as the availability of funding, whether staff can be released, the availability of appropriate training interventions, mentors and assessors. It would not be practical for the centre to be prescriptive on this.

**You may care to show this page to your local MP**

**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. Email Addresses are withheld to prevent Spam. Please send email enquiries to [mg@mgauk.org.uk](mailto:mg@mgauk.org.uk) and we will forward them on.**

Dear Feedback,

As a 69 year old male with recently diagnosed MG, my early experiences with medication (good, bad, good) might be useful to share with your readers. When I started on Mestinon, it seemed a great help at first, but side-effects (stomach cramps, diarrhoea, nausea) became more and more troublesome. I tried Imodium and DioCalm and they helped to some extent but were really not the answer. Then, I asked my GP for Propantheline (as recommended in the MGA Information Pack Volume 1, page 10). He agreed, somewhat reluctantly – and I am so glad he did. The results are excellent, with the side-effects of Mestinon almost completely prevented and no new ill-effects. I take 15mg Propantheline 30 minutes before every alternate dose of 60mg Mestinon. Occasionally, when this is not sufficient, I take two Imodium capsules as well, for complete control of Mestinon side-effects. I am also on prednisolone and azathioprine but that is a longer term story.

My GP was reluctant to prescribe Propantheline for understandable reasons. Propantheline is an anticholinergic (blocks acetylcholine (ACh) receptors) and the last thing we want with MG is to block any of the few remaining working ACh receptors we have left in our voluntary muscles. Why this need not concern us after all, was hard for me to ferret out, and I have not seen it expressed clearly anywhere else, so the main purpose of this letter is to share the following findings with others because they were very reassuring to me.

Acetylcholine receptors are not all the same (this is explained in the MGA Information Pack Vol 1, p 6). Those in our gut (which get over-stimulated by the effects of Mestinon) are known as muscarinic ACh receptors. Those in our voluntary muscles are known as nicotinic ACh receptors. If you are still with me after all this rigmarole, here is the punch line: Propantheline is a muscarinic

antagonist, so it protects the ACh receptors in our gut from excessive stimulation by Mestinon, without blocking the ACh receptors in our muscles which need the Mestinon to help them be stimulated. So, there should be no need to worry about Propantheline counteracting the good effects as well as the bad effects of Mestinon.

Yours sincerely,

JOHN ARCHIBALD, Farnham Royal, Bucks.

*(Ed: You have got it all absolutely right about Propantheline. THANK you for pointing it out to us. We will clarify the point that it is a specific muscarinic antagonist when we next update our literature (Volume 1). Unfortunately, it has just missed an update. We should be mindful that as each patient is different, one person's use of Imodium may not suit others.*

Dear Editor,

I enclose a cheque for £70 raised by my fitness and tap class eating my home made soup! Enclosed is a photo of my tap team taken at the Christmas Show 2004. The 20's number in the gold was our finale. I am the one seated in the centre. I would also like to thank our fitness class who are our great back-stage team. We couldn't manage without them!

JOAN ARMFELD, Addington, Surrey.



Dear Sir,

You asked for comments on the "sufferer v Myasthenic" issue. I couldn't agree more with Paula Francis (no relation as far as I know) when she complained about being referred to as a "sufferer". Of course myasthenics suffer as does anyone else with a chronic and serious condition, but calling one's self as "sufferer" is undignified and embarrassing. When I saw this term used on my first enrolment form I was shocked and in subsequent years have crossed it out – with comments. Positive thinking is an important part of dealing with myasthenics and the term "sufferer" encourages a "poor me" attitude. My neurologist refers with some affection to his "myasthenics" and I notice Gravis used the term. If I had cancer I would refer to myself as "a cancer patient" if I had to mention it at all. Please can we stop being "sufferers" and become what we are "myasthenics".

Yours faithfully,

PAMELA FRANCIS

*(Ed: We only had two responses to the original letter and therefore it does not appear to be of much importance to people. This is not surprising, especially when one considers the larger problem of MG itself. It is not the policy of this newsletter to discriminate one way or the other and therefore the term will continue to be used interchangeable as circumstances and flow dictate and will be permitted when people write in (see previous letter). However, Pamela does make one very important point which I believe is applicable to all people who have a serious illness, and that is to maintain an attitude of positive thinking. Above all else, I personally believe that this will be the single most important thing that you can do for yourself – it costs nothing; requires no medication and can be taken throughout the day without an appointment. You cannot over-dose on it either!*

*I also believe that picking up on very minor issues like what words to use in which circumstances is adopting a negative attitude. If it is a word that you would not choose yourself, then so what? Just move on and try to read the underlying message that is being put across. It is the message that is important and not the words or the grammar or the style. I think we will let it drop there.)*

Dear Editor,

Would you please forward my thanks to Mrs. Eunice West of Kent, for her letter in the Spring edition of the magazine re Travel Insurance. I was actually phoning and having difficulty trying to get, without success, insurance for my holiday to Portugal in May. Glancing briefly through, I spotted her letter and took her advice and telephoned Tesco. In minutes I was booked and also saved quite a few pounds. To cap it all, the man I spoke to has a sister who also suffers with MG. So my thanks to Eunice for this information.

BETTY PHELAN, Oxford

To all my special and dear friends,  
Thank you for the article in the newsletter!!!  
You really are a super bunch of people.  
How lucky I am to have you. I am to go to the Palace on Tuesday 24th May. I am thrilled about the date being "Empire Day" as I remember it. So appropriate for an MBE. We will travel up the day before and return the day after. That will be long enough for London!. I am to speak to the Marks and Spencer Retirement Club at a local hotel during September. Date and Time to be arranged. That is all for now. My love and thanks to everyone.

MARJORIE DIX MBE

*(Ed: Thanks Marjorie but actually you are the "Super One". You do not get an MBE for turning over in bed! Whatever you have, you have earned it. Enjoy your day!)*

Dear Editor,

I was very interested to read the articles on Sir Geoffrey Keynes. In March 1953 I went into East Suffolk hospital for a thyroid operation. Fortunately there was a young doctor there who knew about Sir Geoffrey and I was referred to him in July. I was then 33 and was told it was a good age to have a thymectomy which went very well and I was discharged in August on a low dosage of tablets and I quickly gained so much extra movement which made a big difference as I had two young children. Mr. Piercy was also helping with the operations. Each year my late husband and I would go to the meetings which were held in London and meet and chat with these two gentlemen. They asked me once what medication I was on and I said half a tablet. They said "you can throw

that to the birds", so from then on I didn't take anything – I just needed the courage to do it. I am now 84 and have led an active life and have never taken any medication for Myasthenia. Of course, now I am on blood pressure tablets and I have lately developed a form of asthma. I live alone and cope with most things. I am so grateful to these gentlemen and everybody connected, who enabled me to lead a normal life. I do realise that not everybody is so lucky, but I think being the right age at the right time helped a lot. With many thanks,

Yours sincerely,

JOAN PACKARD, Felixstowe, Suffolk.

Dear Editor,

Brain-Storming Day

I was asked to represent our Branch Chairman at a one day conference held at the Novotel Hotel, near Derby. As I was already staying in the Peak District, I arrived promptly for a 9.30 am start. Finding the car park crammed full of police vehicles, I apprehensively walked into the foyer and was astounded to see police officers everywhere. I thought, "Golly what have MGA arranged here; this welcome is a bit over the top". I later found that they were there on special duty for the G8 conference. As I hadn't been involved with MGA nationally for some time I could not recognise anyone so I walked over to the only group not wearing uniform and luckily found the right people. The day began with informal introductions (some delegates were on their knees – not in homage to the Trustees, but merely writing their own names on a large sheet of paper placed on the floor). There was no set agenda. It was made clear from the start that it was to be very informal, with no "them & us" scenario between the Trustees, Regional Organisers, Staff and Branch Representatives. A full report on the day has been produced for the newsletter so I won't attempt to go into details. I would however, like to say that the day was an excellent way of communicating thoughts, ideas, concerns and worries from all sides and there was definitely not a "them & us" situation. Working groups

consisted of equal numbers of the different parties involved. It was not all serious; plenty of laughter and bantering was also heard. The day was hard but enjoyable with no long 'natural' or tea/coffee breaks. These were all taken 'on the run', so to speak. The hotel supplied an excellent working lunch. Some members took advantage of the nice sunny weather in which to eat their lunch and swap MG experiences and anecdotes. It was good to realise that we all had the same aim in mind:- "To ensure the best care and support for the myasthenic" because at the end of the day that was the reason we were all there and without whom there would not be an MGA. It was good also to put faces to voices/names and yes, some do look as good looking and fun loving as they sound! (as well as very helpful). I would like to thank everyone who helped organise this very worthwhile day as I hope that it will prove very beneficial to everyone within MGA.

LYNNE PITCHER, IOW Publicity Officer

Dear Editor,

I was born in Hamburg when my father was serving in the Army. The doctors said that I might have MG. On returning to England, I attended the Birmingham Children's Hospital as I was having trouble keeping food down and they said my thymus gland was working double time. I was put on Pyridostigmine for a year and then had a thymectomy – the first boy to have one in the UK. The surgeons were Dr D'Abreau and Prof. Smellie. The operation was not a complete success and I was told that if they had taken it further I would have turned to the female side. As it was it stunted my growth and for a long time I could not face bright lights or read for long. Even now I tire quickly. Also, as I was only five, the nursing staff placed a suppressor over my chest to stop me getting out of bed, this put my shoulder out and now I have a curvature of the spine. As the first boy to have a thymectomy I would like to know who was the first girl and how has she coped?

MR. A. RENDELL, Yeovil, Somerset

## Plea to MP over crippling muscle condition (IOW County Press Article)

Members of the island branch of the Myasthenia Gravis Association met island MP, Andrew Turner, as part of their campaign to raise public awareness of the condition and seek support for efforts to fight it. After the 45-minute meeting at Mr. Turner's Newport office, publicity officer Lynne Pitcher said it had been very helpful to the association's aims.

Mrs. Pitcher, her husband Roger, who is branch chairman, plus fundraising officer Pat Stone met Mr. Turner last week.

Mrs. Pitcher said: "We made him aware of the condition, which is known as the rag-doll illness because of its effect on muscles. We also stressed the need for more neurologists in the NHS to diagnose it. It is notoriously difficult to diagnose because sufferers can be fine one day and like a rag-doll on the floor the next. The involvement of neurologists is critical in diagnosis and even they face the difficulty of having to rule out multiple sclerosis, muscular dystrophy and brain tumour. The difficulty is compounded because there is a shortage of neurologists in the NHS. In the House of Commons there is an MP, Jim Dobbins, who has two grandchildren who suffer from the congenital form of the condition. We sought Mr. Turner's support of an information display in the Commons this summer. Mr. Turner was very interested and supportive".

Pic shows L-R: Roger Pitcher (Chair), Pat Stone (FR), Andrew Turner MP, Lynne Pitcher (Pub)

## Project NEPHIRD (Public Health Institutes on Rare Diseases) funded by the EU Commission.

Back in January the Association was approached (via Professor John Newsom-Davies) by Dr. Domenica Taruscio of the Italian National Centre Rare Diseases based in Rome. Dr. Domenica Taruscio's request was for help in conducting a survey to evaluate some parameters related to the quality of life of those who suffer from Myasthenia Gravis and their access to health and social services.

Our sincere thanks to Mary Hawkins, Secretary of the Nottinghamshire Branch who managed the whole process of contacting members. A special thanks to all those members who very kindly completed the questionnaire, frankly and honestly.

The completed questionnaires have since been dispatched to Dr. Domenica Taruscio, when we have feedback from her we will keep you all posted on the outcome, via MGA News.



### SUBMISSIONS TO THE NEWSLETTER

Please submit articles and photographs well before copy deadline date where possible. Edition deadlines (right) are for guidance only. The printer's resources will 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 (photographs get separated from covering letters). 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 and editorial procedures. MAX SHERMAN, *Editor*

Edition	Copy Needed by Date
Autumn 2005	5th August
Winter 2005	11th November
Spring 2006	10th February
Summer 2006	12th May

Region 12 — KAREN CLANCY — Tel: 00353 65 6838 270

E-mail: [karen.clancy@mga-charity.org](mailto:karen.clancy@mga-charity.org)



Here are just a few of the participants who help raise funds for MGA by taking part in the BUPA 10k Run which was held in Phoenix Park Dublin on 9th April 2005. Well done all of you.



Picture on the left shows Padraig Clancy (L) and Rory Clancy (R) lining up for the race.

On the right we see Julie Short and Alan Lyons after completing the 10k Run.



Region 9/10 — BARBARA BUXTON — Tel: 01773 743221

E-mail: [barbara.buxton@mga-charity.org](mailto:barbara.buxton@mga-charity.org)



### Birmingham Branch say "Happy Birthday 'Cool Dude' "

Members of the Birmingham branch gathered for their monthly meeting on 16th April. Betty Evans was thanked for her fundraising idea of MGA's own Universal Trolley Coins. The coins are similar in size to a one pound coin and can be used in supermarket Trolleys and Lockers. They have the MG initials on one side and the Rag Doll on the other. The branch regularly carry out Store Collections and are now looking forward to adding to their success by selling their coins at Trolley points and various venues.

The meeting finished with congratulations to Roy Brittain as it was his 85th birthday that

day. Roy had bought cream cakes for everyone and the branch presented him with a card and a 'Cool Dude' birthday cake. Happy Birthday Roy!

Caroline Roach from Newark's SpecSavers has MG. Despite this, she bravely undertook a Parachute Skydive to raise funds. Well done Caroline!

### Branch News

We have received an Email from Sally Ann Morgan of the Plymouth and Cornwall branch to say that Plymouth Argyle Football club have donated £2,850 to us from the charity shield. This money is to be used in the Plymouth area and will help with funding to the recent regional meeting and future meetings for local Myasthenics.

### Local Newspapers

Beth Elston from Lincolnshire had a very good write-up in her local paper in April where they printed a comprehensive story on her condition and its effects on her life. This article will help bring awareness of the condition to the people living in the area covered by the newspaper.

Beth has also done sterling work in conjunction with her MP and sent us in a list of Questions and Answers which were recently raised in the House of Commons and printed in Hansard. These can be seen on page 8.





Region 13 — RITA GOLDTHORP — Tel: 01980 626062

E-mail: [rita.goldthorp@mga-charity.org](mailto:rita.goldthorp@mga-charity.org)**Did you know?**

You can stop unwanted 'sales' telephone calls by registering with the Telephone Preference Service. Just ring 0800

398893 if you are a BT customer or 0500 730730 for cable services. The Mail Preference Service, to stop junk mail, can be contacted at: DMA House, 70 Margaret Street, London W1W 8SS  
Tel: 0207 291 3310.

Are you thinking about retirement and drawing your old age pension? Did you know that if you defer your pension you could either have an increased pension when you chose to start taking it, or you could chose to have a lump sum payment? There is a guide available called 'Your state pension choice – pension now or extra pension later' and it can be obtained by calling 08457 313 233.

Remember that Myasthenics do not have to

pay for their medication. Is alternative medicine appropriate for you? Check very carefully what any alternatives offer. Reflexology for example is wonderfully relaxing but it stimulates the immune system and may therefore be inappropriate to you.

Do you have a 'blue badge'? many Myasthenics qualify for one. Contact your local council for details of how to apply. Ask your GP or your consultant if your home environment can be assessed by an Occupational Therapist. You will find your local OT very helpful and knowledgeable about the equipment and benefits to which you may be entitled to help your daily life. Meals on Wheels may not appeal or may not be appropriate for you but have you considered some of the frozen ready meals on offer from specialist companies such as Wiltshire Farm Foods? They deliver to your door. All you need to do is heat the meals either in the oven or the microwave.

### Winners of the Megan Doll Prize Quiz (Winter 2004)

Mrs. P. Braund, Bideford, Devon  
Mr. M. Mundy, Trowbridge, Wilts  
Mr. A. Nicholas, Bridgend, Wales

### Winners of the £1,000 Grand Draw 2005

**1st.** £1,000 goes to Mr. D. Jones from Sherborne, Dorset  
**2nd.** £500 goes to Mrs. M. Waite from Dunstable, Beds  
**3rd.** £100 goes to I. Bretherton from Burnley, Lancs  
Runner up prizes go to Mr. T. Rollins from Broomhedge, and Moira and T. Morgan from Hirwaun, Aberdare.

## Bespoke Insurance for people with Myasthenia Gravis

If you are living with Myasthenia, you may have experienced difficulty in obtaining certain types of insurance – particularly Travel and Life Assurance. Not all insurers provide cover in respect of pre-existing medical conditions and where this cover is offered, increased premiums may be charged.

As a result, MGA have teamed up with Heath Lambert, a leading insurance broker in the medical charity sector, to provide Travel and Life Assurance policies specifically for people with MG. These policies ensure you get cover at a reasonable premium.

Along with bespoke policies for Travel and Life, Heath Lambert can also provide policies for Household, Motor, Pet and Caravan insurance. They have negotiated a 10% saving on your current Household renewal premium (subject to underwriting criteria). For more information please ring 01603 828359.

**Heath Lambert are happy to make a donation to MGA for every policy sold.**



Region 8 — STEVE ANNABLE — Tel: 01457 766410

E-mail: [steve.annable@mga-charity.org](mailto:steve.annable@mga-charity.org)

Merseyside Chair, John Evans (pictured) receives a cheque for almost £2000 from Claire Cockburn who supported the branch with a Royal Sun Alliance workout for Children

in Need. The Lancashire branch had Andy McCue to thank for raising £668 when he ran in the Reading Half Marathon – thanks also to Dorothy and Chuck for their help.



Leeds branch were supported by donations of £240 from Lawrence Gaunt's 60th birthday celebrations – thanks to Lawrence, Avril and Bev and all who contributed.

Students at Leeds University, through event organiser Louise Annat (pictured) supported Leeds Branch with a Children in Need Workout raising £1088. Louise was joined by Leeds Rhinos stars and Olympic marathon runner Tracey Morris and Leeds Chair Heather Read.



Staffordshire North Branch are to provide CDs to Opticians and GPs in the Stoke area to help improve diagnosis. South Manchester branch and Great Moor Conservative club joined forces with an Elvis tribute night which with other events raised £2600 – picture shows branch members Bert Jarman and Beryl Reeves with Steve Annable receiving the cheque.



Thanks also to Jack and Mary Handley, Rita and all at the club.

North Wales branch had MG Nurse Kate Fraser as guest speaker at their March meeting (pictured). The branch have already raised funds to translate MG literature into Welsh. Wigan branch received £120 from the

daughter of the late Kathleen Swanton – Kathleen will be sadly missed by all the branch. Wigan also received £100 from Hindley Rotary club – our thanks to Ralph as well.

A surprise birthday party for York Chair Margaret King resulted in donations of £335 from family and friends. York branch have a collection planned for York Races on Sunday September 4th – if you can help contact Steve on 01457 766410.

Helen Carter ran for South Manchester in the London Marathon finishing in an amazing 3 hours and 48 minutes – thanks Helen and Ivy for this support.

South Yorkshire branch also had a runner in the Marathon - Harry Young who was dressed as a Rag Doll (we hope to bring you a picture in the next edition). He was supported by John Hudson (Trailer Supermarket Ltd of Bawtry). Thanks Harry, Sue and Chris Hudson for a splendid job!

The branch also have a supermarket collection planned for Sainsburys in Doncaster on December 2nd and 3rd.

If you can help call Steve on 01457 766410. North Manchester Branch are supplying CDs to the regions Opticians and GPs to help improve diagnosis. Thanks to financial support from Awards for All and Bolton and District Golfers Charity Tournament.

**A note for your diary!** This years Regional Conferences for Lancashire and Yorkshire will be as follows:

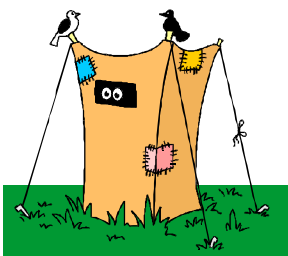
YORKSHIRE – The Holiday Inn, Leeds on Saturday September 10th – hosted by Leeds Branch.

LANCASHIRE – The Holiday Inn ,Bolton Saturday September 17th-hosted by North Manchester Branch.

Invitations will be sent out in August to the regions.



**For details of Drinkers Delights pub Bungee Jumps in West Yorkshire this year call Steve on 01457 766410**



## 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  
First Floor,  
Southgate Business Centre,  
Normanton Road,  
Derby DE23 6UQ

Tel: 01332 290219

Fax: 01332 293641

Email: [mg@mga-charity.org](mailto:mg@mga-charity.org)

Helplines:

UK 0800 919922

Ireland 1800 409672

Websites:

[www.mgauk.org](http://www.mgauk.org)

[www.mga-charity.org](http://www.mga-charity.org)

Registered Charity

**We're on the WEB**  
[www.mgauk.org](http://www.mgauk.org)  
and  
[www.mga-charity.org](http://www.mga-charity.org)

No: 1046443

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## 200 CLUB WINNERS

### Draw February 2005

- 1st: Ms. A. CARLYLE, Cirencester - £60  
2nd: Mr. A. GRAY, Arbroath, Tayside - £30  
3rd: S. & E. COTTRELL, Bebington - £15

### Draw March 2005

- 1st: Mr. D. MACARTHUR, Dornoch, Highland - £60  
2nd: Mr. N. BURTON, Dronfield - £30  
3rd: Mrs. B. BROWN, Poole, Dorset - £15

### Draw April 2005

- 1st: Mrs. I. SMITH, St. Combs, Fraserburgh - £60  
2nd: Ms. H. REAY, Purley, Surrey - £30  
3rd: Ms. C. G. MERRIMAN, Milton Keynes - £15

## PLEASE APPLY/RE-APPLY FOR 200 CLUB MEMBERSHIP TO HELP MGA

(Please complete the form below)

**Please help Margaret by sending in your form as soon as possible.**

The 200 Club 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.

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 2005**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_ Post Code \_\_\_\_\_

- I will pay by: 1. Monthly Cheque/Postal Order (payable to MGA)  Please  
2. Full remittance of £12 enclosed  tick one  
3. Bankers Order (please complete below)  box only

### **BANKERS ORDER**

The Manager (full bank address please)

Please send in today and  
enclose SAE - Thank you

Sort Code \_\_\_\_\_ Account No. \_\_\_\_\_

Account Name \_\_\_\_\_

Please pay to Myasthenia Gravis Association, Account No. 61214950,  
Sort Code 40-33-30, HSBC, 15 Uttoxeter Road, Mickleover, Derby DE3 5DA,  
the sum of £1 per month for 12 months commencing on 1st August 2005.