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AGM Results in New Board Members

At the AGM held in Plymouth on the 26th October 2002 the following members were appointed or re-appointed onto the Board of Directors/Trustees of the Association.

Mr Peter Finney – **Chairman**
Mr Bernard St John Glew – ***Treasurer**
Mr Charles Kodua – ***Treasurer**

Directors/Trustees

Ms Caroline Beetham
Dr Ian Hart
Mr Rodney Haverson
Mr Martin Haworth
Mrs Mary Lane
Mr Ken Poole
Mr Keith Watkins
Mrs Jane Whittingham
Professor Nick Willcox

** Unfortunately, Bernard was unable to carry out the duties of Treasurer for the complete year due to pressure of duties elsewhere, and by the time you read this, he will have handed over to Charles Kodua.*

INSURANCE COVER FOR MYASTHENICS

As many of you will know, we have been researching companies that are willing to provide comprehensive insurance for myasthenics. We are delighted to inform you that we have now made the necessary arrangements for insurance cover to be provided via Heath Lambert Affinity Partnership. Details on page 13.

NEW WORLD LINE-DANCE RECORD IS ON THE CARDS

The event was a great success with participants in the following countries:- England (Isle of Wight 190, Southport 301), Scotland, Wales, Malta, Cyprus, Germany, Norway, Latvia (912), Switzerland, Dubai, Malaysia (190), Japan (160), Singapore, (400+) South Africa (160+), Australia, USA (Florida 8) and Canada. NB. Numbers are still awaited for some countries/towns. We are now awaiting verification of numbers from the various officials who will use video recordings of events with a clock showing local time of start, middle and end of dance. There was enormous Press coverage, plus photographs and of course, sponsorship money. We will bring you further details along with some pictures in the next edition. In the meantime THANKS to all those who participated in this exciting event.

Although Christmas will be over by the time you read this, the Chairman, Directors and Staff send their best wishes to each and every one of you and sincerely hope that you have had a prosperous launch into the New Year. Let us remember in particular those who are separated from their families or who are in poor health at this time and over the festive season; may their life soon return to normal.

The coming year will bring us big challenges and it is up to us all to give the MGA our fullest backing, and in particular, to support any events that are arranged whenever possible.

WHAT'S YOUR POISON? *The debt Myasthenics owe to herbalists and poisoners*

Dr Maria Elena Farrugia, Dr Ian Spreadbury and
Professor Nick Willcox.
The MGA/ MDC Centre, Oxford

In a recent article, we saw how researchers have taken advantage of venoms from creepy crawlies to help us in diagnosis and even treatment. Now it is the turn of the plants. As before, poisons have provided vital starting points for investigating how nerve → muscle triggering works normally, and some have proved even more crucial friends in treating myasthenia.

A brief reminder

(see diagram below):- The *ignition system* of our 'voluntary muscles' depends on the chemical transmitter ACh (the 'ignition keys') which is released when the nerve endings are switched on by impulses from the brain. The ACh then latches into special receptors ('AChR' = 'ignition locks') on the muscle surface – and that triggers the muscle to contract. The spare ACh is broken down by ACh esterase (AChE). The muscle AChR is called 'nicotinic' because it is targeted by nicotine from the tobacco plant (*Nicotiana affinis*). In most myasthenics, *the numbers of these AChRs are too low* – whether because of an immune attack or an inher-

ited fault.

Licensed to kill...

How poisoned darts helped to explain the defects in MG ...

Many poisons belong to the large family of 'alkaloids'. One key player is 'curare' (it rhymes with Harare in Zimbabwe). It has long been used as an arrow poison by South American Indians (eg in Ecuador and Peru); its name means a venomous decoction, and it is boiled down from the barks of various trees. Sir Walter Raleigh and others mentioned it, but its preparation was first described by the versatile Alexander von Humboldt, in 1807. He was one of the last universal scholars in the natural sciences – not only a geographer but also a naturalist, botanist, author, artist and sociologist. Derived from the trees *Strychnos toxifera* or *Strychnos guianensis* and *Chondrodendron tomentosum*. (See Fig 1), curare was used so much by warring tribes and hunters that it was very valuable. Using arrows and silent blowpipes, they could kill birds in only ~ two minutes, small mammals in ~ 10, and larger ones in ~ 20 minutes.

The famous French researcher, Claude Bernard, discovered in ~ 1855 that curare paralyzes voluntary muscles but not the heart, and kills by stopping breathing. He concluded that it affected nerve → muscle triggering. We now know that it simply blocks nicotinic AChRs, and so makes muscles floppy – exactly as in MG when the AChR numbers are too low.

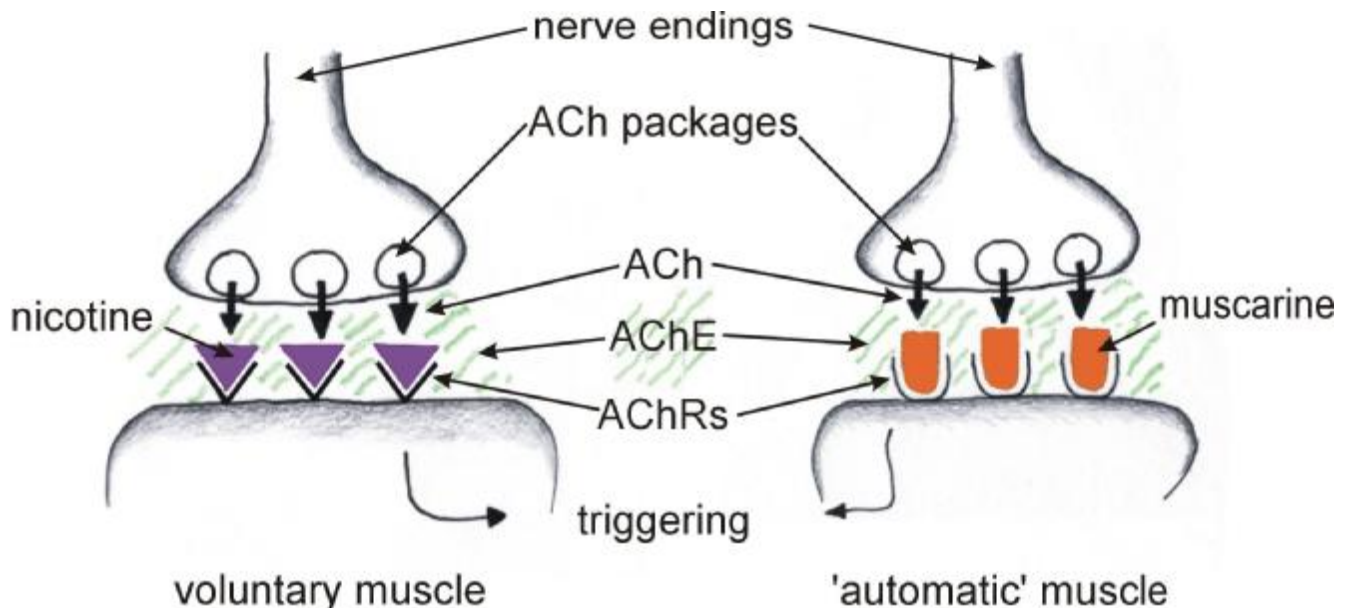


Fig 5 Nicotinic and muscarinic receptors- the differences

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..... and to save lives...

Now we come back to our heroine, **Dr Mary Walker**. You may remember (from the last issue of MGA News) that she was discussing a new myasthenic (with the Neurologist Dr Denny Brown). They came to the conclusion that myasthenia seemed like poisoning with curare – to which myasthenics are super-sensitive. Desperate for some treatment – because MG was then often fatal – she injected another plant drug, physostigmine, because it had been the best known curare-antidote since ~ 1900 (as shown by the Viennese Dr J Pal). When she tried it, the patient improved dramatically, a breakthrough she published in the *Lancet* in 1934. That drug is very similar to 'Tensilon', and is a short-acting version of the myasthenics' dear friend **Mestinon** (properly called **pyridostigmine**); this relative of physostigmine was first used in 1954. Mary Walker quickly realised that these drugs worked by blocking AChE, so delaying the breakdown of the ACh and boosting its chances of triggering the muscles – rather like using more choke when the car is cold.

Physostigmine comes from the West African Calabar bean (*Physostigma venenosum*), and was used there for trial by ordeal, rather like ducking suspected witches under water in this country. (See Figure 2 and 3). In Edinburgh in ~ 1855, it had been shown to constrict the pupils (by enhancing the effects of ACh, as we now know).

In 1927, an American myasthenic, Harriet Edgeworth, tested another herbal drug on herself called **ephedrine**; for the next few years, it was the best hope for myasthenics. It soups up the muscle ignition slightly because it mimics the effects of adrenalin – the 'fight, fright, flight response' that you all know so well (pounding heart, sweating, hair standing on end...). It also helped Harriet to tolerate heat much better.

Ephedrine is derived from various *Ephedra* species, especially *E. sinica*. Also known as *Ma huang*, it has been used in Chinese medicine, probably as far back as 2800 BC, to treat colds and asthma; its cousins are still used as de-congestants for 'bunged-up' noses and asthma. Ephedra was used by the Zen monks to encourage calm concen-

tration during meditation and by Genghis Khan's bodyguards to keep them alert on sentry duty. Other alkaloids have less desirable side-effects; some are dangerous in MG, eg muscle relaxants or pain-killers such as Acetaminophen and Oxycodone, and also some herbal remedies.

Understanding the side-effects of mestinon...

Many 'automatic functions' also depend on ACh as transmitter; they include pupil contraction (in the eye), slowing of the heart and stimulating gut and bladder movements. They are not affected by the MG, because these 'muscarinic' AChRs are completely different from the nicotinic AChRs in muscle; unlike them, they are stimulated by the toadstool poison, *muscarine*. (See Figure 4). Its effects include diarrhoea, gut cramps and sweating – rather like a mestinon overdose (see below). It is one of several poisons in a toadstool you know well – the one with the red cap and white spots beloved of garden gnomes – the Fly Agaric (*Amanita muscaria*). Figure 5 shows the nicotinic and muscarinic Acetylcholine receptors.

.... and treating them too...

Two lovely big eyes? The 'automatic' effects of ACh are normally stopped when it is destroyed by AChE. But they can get out of hand if the AChE is blocked too much by overdosing with Mestinon, which can cause gut over activity and diarrhoea – rather like muscarine poisoning – as many of you know only too well. Luckily, we can reduce that with yet another plant poison, **atropine** or its cousin **probantin**. These drugs block the 'automatic' (muscarinic) AChRs without affecting the (nicotinic) AChRs in the muscles, (see Figure 5) and therefore block these Mestinon side-effects selectively. They also help to speed up the heart and dilate the pupils.

Atropine comes from a plant you probably know, Deadly Nightshade (Figure 6a and 6b); it was called *Atropa belladonna* because the wide pupils enhance the beauty of a comely girl. It is now used as a 'pre-med' before anaesthetics/surgery because it dries up the juices in the mouth and lungs, and so

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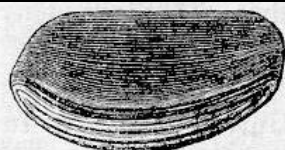
prevents blockages and infections in the airways.

In conclusion, no matter how lethal such poisons may be, they may well have their uses in diagnosis and treatment. What is more, we should all be grateful to all the herbalists, collectors and researchers for investigating them. *How many further valuable drugs are now at risk because of extinctions?*

LEGENDS



Fig 1 one of the curare trees
Strychnos toxifera



Calabar bean; fruit of *Physostigma venenosum*.

Fig 2 the Calabar bean



Fig 3
Physostigma venenosum

Fig 4 Amanita muscaria (Fly Agaric)

Not the best specimen in the world, but this is the classic toadstool from fairy tales and impossible to misidentify. The white spots are the remnants of a 'veil' which covers the young fungus and can wash off in the rain. This is ever so common. All you have to do is find some silver birch trees in autumn and you will almost certainly find one of these not far away.



Fig 6a, 6b Atropa belladonna (Deadly Nightshade):

large oval-shaped leaves, with purple bell-shaped flowers and black/purple berries. This perennial branching shrub grows up to 5 feet tall with 8 inch oval leaves; they are smaller in older plants.



Feedback

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.

Dr Mary Walker.

Following the article on Dr Mary Walker, we have received a lot of interest, none more so than from Sylvia and Harry Elliston (pic below). Harry writes to tell us that Sylvia has had MG since the age of 17 years (now aged 87) and regularly corresponded with Dr Mary Walker and also Dr Laurent (whose wife was a sufferer). He has sent details of his and Sylvia's life (far too much to show here, unfortunately), together



with an original letter from Dr Walker (September 1961) and a copy of an article reprinted from the British Medical Journal 7 April 1973 entitled "Some Discoveries on Myasthenia Gravis: The Background". This article is copyright so I am afraid that you will have to obtain copies directly from BMJ - please do not write to MGA. However, I am sure that if any person was interested in obtaining Sylvia and Harry's life story with copies of the letter from Dr Walker they would only be too happy to oblige. Please write to them via MGA and we will forward your letters on (*please do not seal them as we will have to read them first*).

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This is a transcript of her letter as best as we are able to decipher it. Please remember that it was written in 1961 and opinions may well have changed since then. It may be of historic importance to some people.

Wigtown, Scotland
Sept 18th 1961

Dear Mrs Bates

Thank you very much for your letter. Dr Fergus Ferguson came to see me to get Particulars of my work with Pyrodistigmine not for any other help with his address. He seems to think that thymectomy has been overdone.

I am not convinced that thymectomy has any influence whatsoever on MG, and it was for my own interest that I asked Ruby Weston the questions about it. The estimation of its effect is made more difficult by the fact that since thymectomy became the vogue 1939-1942, all the large clinics seem to have it done on some of their cases. Before that only smaller series of cases in which thymectomy has never been done have been published. What would settle the question is for some eye clinics where thymectomy is never done to compare these results over several years with those of the clinics where it has been done.

I shall be most interested to read ?? article (name of someone). Give her/him my kindest regards
Yours sincerely, M. Walker

Dear MGA Newsletter,

I am an MG sufferer, having been diagnosed in 1977 at the age of 77. My first symptom was when my eyelids dropped which was very scary for me, as I had lost the sight in one eye in a swimming pool accident some years before. Fortunately for me, my ophthalmic surgeon recognised my symptoms and immediately gave me the tensilon test which confirmed his suspicions. He put me on Mestinon and in two months my eye muscles were working again. Two months later, I developed full blown MG. I was taken into hospital in the USA where I live for half of the year. I was given plasmapheresis, and that was followed by removal of the thymoma. A month later, I had a course of Ivig treatments. For the past four years I have been stable although I am still on steroids and Mestinon, and I live a full life and am able to do whatever I want (although I do tire easily—but who doesn't at my age?) I am a member of the MG Foundation of America and receive their newsletters but I want you to know I particularly enjoy the Feedback Section of your newsletter. I completely agree with David Tucker Williams when he says "would that I had someone to talk to over the 3 years before I found MGA. I know what it is to be told you have a rare incurable disease and no-one to talk to". Thank you for the wonderful work you are doing.
Marjorie Bloom, Barnet Herts.

Dear Editor

May I respond to your request in the "Feedback" section of the Autumn 2002 issue and reply to Wendy Wakefield. I am a doctor and I have MG, which was diagnosed in 1991. First, let me say that it is impossible to make any judgement about the treatment she describes from the few details listed in her two published letters.

No doubt, in previous letters to you and to the team at Oxford, she has been able to supply more information.

Secondly, I ask why it is that I have been unable to trace any account of Dr Lechin's methods and results in any medical journal. Has he reported his work at a medical meeting or conference on MG? If not, I would ask why he chooses not to make available to MG sufferers world-wide the benefits of a regime which have enabled people such as Wendy Wakefield to progress to the extent of being discharged from follow-up. I think any doctor who has an effective treatment which he or she chooses to keep secret, while charging a large sum of money to the recipients, is in breach of his or her professional oath, and will remain under suspicion of profiteering or charlatanism until he or she shares fully with the world his or her inspiration. (What a contrast with Mary Walker, described in your lovely article in the same issue).

May I suggest that Wendy Wakefield asks Dr Lechin to write an account of his approach for the MGA newsletter so that we can begin to judge for ourselves whether or not we want to take advantage of his treatment?

Finally, let me say that I have been on treatment with steroids and azathioprine for over ten years now, and am very grateful to those who developed this treatment. It has enabled me to resume my career, and to live a very full and active life, including swimming and riding my bike. Steroids get a bad press because of their side effects, but perhaps we should remember that there is no such thing as a free lunch, and that we should be prepared to balance their advantages against the disadvantages. For me, it is well worth the effort of watching my diet, of exercising regularly, of taking Alendronate to avoid bone-thinning, and of putting up with

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sleeplessness, thin skin, changeable mood, etc, as a small price to pay for no longer being wheelchair bound and unable to swallow.

Yours sincerely

Dr Stanley Freedman, France

Dear Editor,

Thank you for your newsletter which arrived a day or two ago which we will pass on to the doctor looking after Ted from now on. Our Minister of Health who has made such wonderful promises of 'healthcare for all' has seen fit to close the neurology department at George Hospital 'because of lack of funds', so Dr Thorne who was paid peanuts anyway and did the job for research as well as compassion is no longer there to treat people like Ted. Grrrr! He served a vast area almost the size of England and patients who need specialised treatment now have to travel to Cape Town almost 500 kilometres away. It really is a pathetic state of affairs. Ted however has had the benefit of Dr Thorne's treatment for almost 3 years and has been stabilised and is keeping well with just the MG fatigue and leg muscle weakness to content with. He celebrated his 80th birthday in August and at his party I received a certificate entitling me to sleep with an octogenarian! Consideration hey.

Best wishes to all the wonderful people who do so much for MG people.

Ted and Kay Schroeder, South Africa

Dear Sir,

Thank you for sending me the MGA Welcome Pack and inviting me into your family. I have only recently been diagnosed with MG, having suffered in silence for about 3 years. Initially I was glad that the diagnosis wasn't multiple sclerosis, but I am left with confusion, having to learn about a disease that I had never heard of before. I am presently taking pyridostigmine and prednisone, which I'm building up gradually. Unfortunately, the first is causing terrible diarrhoea and vomiting whilst the later is making me feel weaker than ever plus bouts of tears! My consultant is expecting me to have a thymectomy within the next 12-18 months. I am luck to have a good network of friends and loving family all of whom are making life bearable at the moment. My sister, the computer expert, is busy searching the internet sites and I swear she knows more now than my consultant. My dad,

bless his cotton socks, is intent on suing the world! I haven't got the heart to tell him just yet that he is wasting his time because it gives him something to do. My mum has introduced a cleaner into my home, and she irons too! My friend call daily to keep me smiling or to offer a shoulder to cry on. Even with all this support I feel lost. Whilst reading your newsletter made me cry it was also comforting to know that there are others out there just like me. I don't want to be in your family but I am and you've welcomed me with open arms, so thank you.

Caroline Simpson, Oldham, Lancs

Dear Friends at MGA

As a sufferer of MG, I wanted to write to you at long last to tell my story of how I cope with MG and what I have achieved, so as to give hope and strength to other sufferers. I was diagnosed in 1987 (age 31) at a time when I had just gone through a particularly nasty divorce. I had a 3 year old daughter to bring up on my own and I did not know what the future had in store. My symptoms came on slowly, at first I could not peg things on the washing line, then I could not hold the hair-dryer for long. I ignored these symptoms for 6 months then my eyes began getting weaker and drooping, my legs were weak after walking even short distances. So I went to my GP who openly said he did not know what was wrong with me, but sent me for tests where I became an 'in-patient' for 3 days before diagnosis confirmed MG. I was prescribed Mestinon 30mgs (half a tablet) 3 times daily which I still take. I have always led a busy life and continue to do so, but I do respect the signs and symptoms my body gives me and often go to bed early when my body 'runs out of energy'. I had a thymectomy in 1995. The symptoms persisted even though I was looking forward to being a lot better within 2 years. When I look back over the years I can remember New Year's Eve 1999 when I actually danced all night without my legs feeling weak or giving way. Jubilation!

Jan Taylor, Leigh-on-Sea, Essex

Tel 01702 529571 or email ian@hom-remedy.fsnet.com.uk

(Ed. Jan's letter described her travels though life whilst obtaining her diploma in Homeopathy. Unfortunately there is not enough space here to tell it all. She does offer her telephone and email details if anybody would like to contact her. In particular,

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she would like to make contact with Wendy Wakefield).

Dear Editor

I don't have MG and I have no connections to anyone who is a myasthenic. I didn't even know of such a disease until now, but now I do and I would like to help. I am 18 years of age. I do not have a chequebook or credit card so I have enclosed my registration fee in cash to enable me to participate in the Marathon to raise fund for MGA. If I am selected I will raise as much money as I can, which I can guarantee will be at least £1,500 and probably more. If I can set an example perhaps others might follow. You probably wonder why does this kid care so much as he has no connection to anyone with the disease. Well, I was quite emotional when I read your info package. It made me sad and I wouldn't want anyone I care for to contract this disease. There is no cure and no one I know has even heard of it. I would not like it to stay that way. If my donation helps or if there is anything I can do then please let me know. I saw your poster as an act of fate. I am going to run marathons anyway for fun, but if I can help people whilst at the same time doing what I enjoy then that makes it even better.

Mark Fuller, Loughton, Essex

Dear all at MGA,

Information for children and families with MG

I am a paediatric neurology outreach sister working at Guy's Hospital. I have developed a special interest in MG and congenital myasthenia working with Dr Stephanie Robb. We have set up specialist paediatric myasthenia clinics that run each month, and I have regular contact with as many children and families with MG as possible! Part of my role also involves regular teaching for schools and other professionals involved with MG, so I have produced some written information to give to these professionals.

I can be contacted Monday to Friday on the following numbers 0207 955 5000 extension 3752.

Regards, Debbie Komaromy

Paediatric Neurology Outreach Sister

Guy's & St Thomas' NHS Trust

Email: Debbie.Komaromy@gstt.sthames.nhs.uk

Dear Max,

About 4 years ago I wrote to your magazine about my beautiful golden retriever Charlie who was diagnosed at 2 with MG. I thought you might like an update on his progress. He is now 6 and doing very well. He is still on his original dosage of 1/4 tablet mestinon twice a day, but eats hard dry food, biscuits and anything we give him. Although he has tendonitis in his shoulder at the moment, caused we think by rolling on the ground playing with his brother, otherwise he really loves life and is a joy to own. He is still a Pets as Therapy Hospital Visiting Dog and although grounded at the moment with his shoulder as I can't exercise him fully at present, leads a full and normal life. Our vet hopes because there has been no deterioration in the MG during the last 4 years this should continue. Also apparently dogs can get better from this disease, although a recent test showed that this is not the case with Charlie. Thank you for sending me your magazine and I wish all the best to MG sufferers out there including any canine ones.

The last time your printed my letter, I received two lovely replies - one from a lady who was an MG sufferer herself with whom I still exchange Christmas cards, and another lady whose own dog had suffered from MG. My own local vet is very interested in MG as it is so rare in animals and finds out as much as he can for me.

Best wishes

From Margaret Bramall, Evesham

marg&yorkie@ferryview.fsnet.co.uk

To whom it may concern,

I have suffered from MG for 2/3 years now. I had a thymectomy very soon after it was first diagnosed and this, together with steroids and Mestinon, gradually alleviated many of the symptoms of the disease such as ptosis, the inability to lift my arms above my head, speech and eating difficulties. The disease seems to have 'settled' in my respiratory muscles at the moment. I would go so far as to say that it is in remission (I hope). However, and this is the point of my letter, I do get depressed by both the illness and various other things that 'stress' me (mainly domestic). I approached my doctor about the stress problem and was prescribed fluoxetine (Prozac). I took this for about two weeks and noticed that my eyes developed ptosis again (I had not had this since the onset of

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the illness). I noticed it because my main hobby is photographing rare birds, and I could not look through my binoculars, telescope or camera viewfinder without my eyes shutting. I decided that the prozac was to blame and came off it. Since this decision was taken (independently of my doctor) I have noticed a dramatic improvement. I merely pass this bit of information on to you in order that you can document it and pass the information on to whoever might find it useful. If you wish I can give a talk on my travels, to various countries, in the pursuit of rare and common birds, to any branch of the association. I have a particularly good lecture on Madagascar, accompanied by many slides of the people and wildlife of the island. If this could raise funds I would willingly do it for free. Ptois did not seem in any way connected to the fact that Prozac is supposed to relax you. It seemed to do the opposite. My eyes were particularly sensitive to sunlight as well. I can travel as far as is necessary, if people would like to hear my talk. If it was organised to attract both MG sufferers and wild life enthusiasts it could raise funds for the association. I have been to Texas, India, Alaska, Africa and am going to Namibia in November. I try not to let MG get me down and have set myself goals to achieve as a way of combating the psychological effects of the disease. Obviously I am not as badly affected as many sufferers but given the fact that I was a very active rock climber

(climbing extreme grades at 58) the disease was a massive blow psychologically.

Anyway, enough of this whinging, if you pass my details on to anyone who is interested they can contact me via email or in writing via head office

Mike Richardson, Doncaster

Email: MCHASRICHARDSON@aol.com

Dear Editor,

Hi, I am trying to make contact with Mrs G Smith of Wittering Peterborough, Cambridgeshire who replied to me following a letter I posted in your news letter last year but since then she appears to have moved. If she reads this, could she please make contact with me again, either via my email address or via Head Office

Richard Payne

Email: myasthenicsyndrome@tiscali.co.uk

Dear Sirs,

What a character this Mr Gravis is. I will vouch for what he has written this time as I have often stated that outsiders (other people) only see me when I fall. I can get out and do what I want to do with reasonable ease. Even then if I have to walk any distances by the time I'm on my way home MG is beginning to show! I do not do much for the rest of the day. To help me at times I stop at a shop window for a few minutes - a short rest. I use a tall stick. A normal one would allow my elbow to bend if I felt weak thus I would find no support. So the taller the stick allows my arm to be hard, and gripping the head of the stick I manage to stay on my feet. I cut the stick from a hedge that had a hazel nut branch in it. But that is not why I have written. Mr Gravis states that myasthenics do NOT respond to a SIGNIFICANT change in steroids like other folk. Since we moved to our present address my doctor has shown great interest in MG. I am his only patient. Am I lucky this was 7 years ago. Since then I have had good spells and bad spells.

When I felt there was something wrong with me, my whole body would feel very uncomfortable as if I was losing my stability and control. After I explained as best I could. I said. "Why don't we try higher dose of Prednisilone". (I was currently on 2 per day). So we agreed on 6 per day for a week to see if it made any difference. I wasn't sure but the next day I said to the wife something has happened, it's a change for the better, things are settling down yes, this feeling continued, so 2 days after I felt this change I cut out one tablet, for a week. All ok. So each week I cut out another tablet till I was back to 2. So far so good. I kept feeling good, not perfect, but I was doing things and enjoying a good spell. Thank you doctor. This lasted nearly a year, when the same symptoms hit me again. We decided to try the same thing again up to 6 tabs. I must say here that I was introduced to steroids over 30 years ago. The Plasma treatment didn't work. My blood clogged the pipes and they only got a little in the bag. A "fluid" is all I can call it. So another 6 days and the same feeling surged through me and after a week I was reducing down again. Till I was back to 2 a day this sort of thing happened 4 times in all and each time to the day, the surge of the life surged through me.

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I have gone over 2 years with a dose of 2 tablets a day. So far, with resting, when I don't feel I can do anything I have managed.

Mr Gravis, I have noticed there are not many MGs who have the exact same medications. No two sufferers are exactly the same; this forms the question: Why are sufferers of MG not the same? We could be but we are not. Just for a laugh can you tell me what the difference is between - A MG and An MG. Answer: A MG is a sufferer of MG and moves very slowly at times. An MG is a car and goes very fast at times. Ha! Ha!

From Mr Osborne, Maidstone, Kent

In September this year 500 MGA posters were displayed at various locations on the London Underground. Fortunately, Viacom, the giant media company supported our efforts by not charging the MGA. The posters advertised the fact that we had guaranteed places in the London Marathon. With over 100 applications received to date we are absolutely delighted with the response. We hope



Edition	Copy Needed
Spring 2003	7 Feb 2003
Summer 2003	9 May 2003
Autumn 2003	8 Aug 2003
Winter 2003	7 Nov 2003

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

• HOSPITAL CHARTS

- She has no rigors or shaking chills, but her husband states she was very hot in bed last night.
- Patient has chest pain if she lies on her left side for over a year.
- On the second day the knee was better, and on the third day it disappeared.
- The patient is tearful and crying constantly, she also appears to be depressed.
- The patient has been depressed since she began seeing me in 1993.
- Discharge Status: Alive but without my permission.
- Healthy appearing decrepit 69 years old male, mentally alert but forgetful.
- The patient refused autopsy.
- The patient has no previous history of suicides.
- Patient has left white blood cells at another hospital.
- Patient's medical history has been remarkably insignificant with only a 40 pound weight gain in the past three years.
- Patient has waffles for breakfast and anorexia for lunch.
- She is numb from her toes down.
- While in ER, she was examined, x-rated and sent home.
- The skin was moist and dry.
- Occasionally, constant infrequent headaches.
- Patient was alert and unresponsive.
- Rectal examination revealed a normal sized thyroid.
- She states that she has been constipated for most of her life, until she got a divorce.
- I saw your patient today, who is still under our car for physical therapy.
- Both breasts are equal and reactive to light and accommodation.
- Examination of genitalia reveals he is circus sized.
- The lab test indicated abnormal lover functions.
- The patient was to have a bowel resection. However, he took a job as a stock broker instead.
- Skin somewhat pale but present.
- The pelvic exam will be done later on the floor.
- Patient was seen in consultation with Dr Blank, who felt we should sit on the abdomen and I agree.
- Large brown stool ambulating in the hall.
- Patient has two teenage children but no other abnormalities.
- (From the Business Trader April/May 2001)

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.



LIFE WITH GRAVIS

When I last wrote I was foolish enough to say, "I am turning the corner and am slowly getting back to normal". I was turning the corner,

but what I didn't know was that there was another dip just round that bend. I seemed to develop what the late Douglas Adams (*The Hitch Hikers Guide to the Galaxy*) would have referred to as 'Military Academy Syndrome' (MAS); bits of me kept passing out. For instance, I developed a sore eye, which was said to result from myasthenic weakness affecting the way my eyelid moved, causing an uneven tear film on the surface of my eye. This left dry areas, which became inflamed. Artificial tears were recommended and seemed to do the trick. There were a number of other minor 'systems failures'. When I develop MAS I tend to grunt, groan and mutter, I find this helps me cope with what ever it is that is afflicting me at the time. Mrs Gravis finds this annoying, ever concerned she asks, "what's wrong". I reply, "It helps to mutter", and then add fuel to the fire by saying, "you must learn to tell talk from mutter". I suppose you have to be of a certain age to understand that last reference, but I am sure that the more mature reader will be able to explain it to the more youthful.

Fortunately, by the end of September I had recovered enough to go with Mrs Gravis and our very good friend Brian, on holiday in Cornwall. We stayed on a farm just outside Truro, where the guestrooms are in the old, granite, cow house. The special thing about these is that the conversion has been done to accommodate disabled and able-bodied guests. The high point of our stay was a visit to the Eden Project, which really is disabled friendly. On arrival, displaying my Blue Badge (used to be orange until the EEC interfered) we were directed straight to a disabled car park near to the entrance. There were ramps everywhere and manageable gradients for the wheel chair. Once into the Project I found that I could descend gently down into the old clay pit in which the Biomes are built and, once there, could access them and get as close to all the plants as anyone on foot. The only bit that I could not manage was a climb through some plants at the top of the tropical

dome. To be honest Mrs Gravis and Brian were welcome to that bit of mountaineering, even sitting in a chair it was very hot and humid.

October saw Mrs Gravis and I undertaking another long journey, this time to the MGA AGM in Plymouth. We have always gone along when we could, we missed last year because Mrs Gravis had just had her cataracts sorted and couldn't drive. This year she can see all too well, so we had no excuse. It was wonderful, to trundle into the reception area of the Council Buildings and meet all our old friends. Myasthenics being a rare breed, we are spread so thinly that it is difficult to get together and it is good to be able to compare notes. I kept looking round but there was one face missing, Max Sherman. I was soon told that he had other business to attend to, congratulations Max and the new Mrs Max.

As always I came away from the medical talk, given this year by Dr David Beeson on the progress into research into aspects of genetically caused myasthenia, having learned yet more about MG. Although my MG is not of the inherited or genetic type, I did learn why I am advised not to indulge in a Gin and Tonic, or any kind of tonic water based drink for that matter. It seems that quinine, a constituent of tonic water, can block the ACh receptors that have been left free by the ACh receptor antibodies. Life just ain't fair.

During the AGM there were several points at which I wanted to pipe up and add my two pennyworth. I was prevented, partly because MG had literally got my tongue, but mostly because of threatening gestures from Mrs Gravis, and I know my place.

The one thing that I always do at the AGM is to visit the promotional goods table and stock up with a pillbox or two. Like quite a few myasthenics I have several tablets to take during the course of a day, mostly Mestinon. To help organise myself I use one of the seven compartment pillboxes and put labels showing the swallowing times on the lid of each compartment. In my case seven slots is just the right number. The labels tend to come off after while, but I have been at it so long now that I know that Sunday equals when I get up

(Continued on page 11)

(Continued from page 10)

in the morning, and that Monday is mid morning and so on. With an elastic band to keep the lids closed I can pop this in my pocket and am supplied with medication for the day, wherever I go. At night, just before getting into bed, I refill for the following day. I can't claim the credit for this system, my 'named nurse' Lorna taught me this as part of my 'self medicating' training before being discharged from hospital. To help keep track of where I am with taking steroids on alternate days, I mark the calendar with an 'S' and the dose. I keep a second box, made up with a day's supply hidden in a locked compartment in the car. All medication must be kept secure, an overdose of mestinon would be most unpleasant. This way if I should go out and leave the main box behind I am covered. The other thing I keep in the car is a bottle of water or a small carton of fruit juice. I then have something to take the tablets with.

November 2002

BOTOX BEAUTY TREATMENT

Denise Honeyball wrote in to inform us that a recent article in the Now Magazine about BOTOX mentioned that it was not suitable treatment for anybody suffering from MG. If you are thinking of having this beauty treatment (which is now available on the high street) be aware of the fact that it may have adverse effects on you. As always, if in doubt, contact your GP.

AN ALTERNATIVE VIEW OF THE HISTORY OF MEDICINE

2000 BC - Here, eat this root
 1000 AD - That root is not healthy. Say this prayer
 1850 AD - That payer is superstitious. Take this potion
 1930 AD - The potion is snake oil. Swallow this pill
 1980 AD - That pill is ineffective. Take this antibiotic
 2000 AD - The antibiotic doesn't work anymore.
 Here, eat this root.



On October 10th, 2002 the first Mary Walker memorial lecture took place at the Queen Elizabeth Hospital London. The lecture was given by Professor Aiden Halligan, Director of Clinical Governance for the NHS. Professor Halligan talked about clinical governance and the implications for conduct within the NHS. The lecture was preceded by a five minute introduction by Dr J D Johnston on the achievements of Dr Mary Walker in the treatment of myasthenia gravis. The memorial lecture was a great success and it is hoped to become a regular annual event, which will help perpetuate the memory of Mary Walker and her pioneering work in the treatment of myasthenia gravis.

Pictured above from left to right are; Dr Dirk Meerstadt Consultant Paediatrician, Dr J D Johnston Consultant in the department of Biochemistry & Haematology, Mrs Pamela Furtek (guest of honour) the niece of Dr Mary Walker, Professor Aiden Halligan and Mr Craig Leitch Director of Medical education at this trust.

Behind this group (on the wall), is a plaque of Dr Mary Walker showing a photograph of her with one of her myasthenic patients and a list of her achievements and publications.

Photo from Brian Houston and Dr Johnston and copyright the Department of Medical Photography, Queen Elizabeth NHS Trust, London SE18

A lady recently made enquiries about a Timer which was capable of being set for several times each day (to act as a reminder). Since then, we have come across an item which may be suitable (Electronic Pill Case Timer) sold by Health & Comfort on 0870 054 66 55 (Code Ref 1025—£9.99 each. Alternatively, contact Joy on 01332 290219



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

Martin Howarth, Chair of Lancs Branch, receives a cheque for £275

from a Whist Drive helped organised by **Michael Shepherd** of the village of West Bradford in the Ribble Valley. **Lancs**

AGM guest speaker was **Dr Mark Roberts**. **Steve Greenaway** from



Representative of the Lancashire Branch - Winners of the Charles Read Memorial Trophy 2001/2002 by raising £8,150 for the Association. Our grateful thanks to all those who have worked so hard on behalf of myasthenics



Burnley with Senior and Junior winners of an MGA Fishing Competition in September. £400 was raised. Prizes were donated by **Brian**



Rourkes Ironsmiths, SBS Electrical and Kavia

Plastics. Junior prizes came from **Roger Spence**, President of Burnley Golf Club. **The Aintree Zip Slide** raised £1,500 in September. **Zoe Burgess** (pictured) took part raising £500. Support came from **Craig Bradford** South Manchester Branch, **Alison Lee**, Wigan Branch and **Brenda Craigen** Lancs. Branch. **Graham McGuire** ran the London Marathon, **Eileen Evans** raised £100 making and selling Disney embroidered cushions and **Fred and Margery Fry** donated a decorated cake for the raffle held for the **Merseyside Branch** at the Regional Conference in Liverpool. **North Manchester** has a new chairman in **Christine Morris** of Bolton. **Leeds Branch** have a new secretary in **Clare Hunter** and held a stall at Otley Lions in September. **York and Hull Branches** are planning a social for late Feb. Tel Margret King on 01759 37155 for details. **Wakefield Branch** are to supply Opticians and GPs with medical videos to help improve diagnosis. **Brighouse** held a successful Chocolate & Cakes Party & are looking at staging a Charity Dinner for March. **South Yorkshire Branch** had **Dr Andrew Gibson** as guest speaker. Thymectomy versus medication is a possible new 4 year study involving 35 centres, worldwide. Dr Gibson's hospital – the Royal Hallamshire in Sheffield is one of five selected in this country.



Region 9/10 - Carl Brooks Tel: 01603 665487 Email: carl@mgauk-region-10.org.uk

A big thank you to everyone who took part with the

Parachute Jump on the 20th of October, Pictured left to right are Andre, Amy and Daniel all from the Carrefour Gym in Norwich, Norfolk. We will be holding a parachute jump on a monthly basis, so if you would like to get involved or know of someone who would then please contact me on the above telephone number.

Cambridge Parachute Jump



NEW BRANCH!!!!

A meeting was held on the 19th of November to establish a new branch in Suffolk. The following people have been voted onto the committee:
 Luke Graves (Chairman) Ambrose Jones (Vice Chairman) Andrew Thomas (Secretary) Anna-Marie Arthur (Treasurer) for further details and for information on meetings please call me on the above telephone number.

London to Paris Bike ride

I have agreed to take up the challenge and ride between London and Paris in August 2003.

From my region I will be joined by Steve Vyse who's sister-in-law suffers from MG and Anna Smith who's fiancé also has MG. We will be covering a distance of 285 miles over a five-day period. Passing through picturesque Kent countryside, we cross the Channel and continue through the small villages and medieval market towns of Northern France. We pass through the famous battlefields of the Somme and Agincourt. With long days in the saddle and some strenuous hill-climbs, the sight of the Eiffel Tower, our finishing point, will evoke a real sense of achievement. If you would like to sponsor us please contact me on the above telephone number:



Helpers Natalie Berry (left) and Charolotte Nathan

Notts Branch had a very good write up in the Neighbourhood News when they received a generous cash award of £500 presented by the Mayor of Broxstowe, Councillor Jan Thorley during a garden party at Bramcote. The award came from the Grays Trust (part of the Notts Charities Foundation). Additionally, the garden party itself raised £300 and was enjoyed by many members and supporters, including the founder members of the Notts Branch, Bette and Barrie Nathan.



Beryl Watson, Chair of Tyne Tees Branch accompanied by fellow myasthenic Colin Tingle presenting a medical video to Mr Morton, optician of Thornaby, Cleveland. Local press latched on to the story and ran a special feature which helped raise awareness.

New insurance services for MG members

For people living with MG, finding meaningful insurance products from companies that understand what it means to be living with the condition is often difficult, if not impossible.

Now, through a special arrangement with Heath Lambert Affinity Partnerships (HLAP) and MGA, HLAP is able to offer insurance products and financial services at competitive prices for members, their family, friends and supporters.

What's available? Life Assurance and Household insurance are available now, Travel Insurance will be available in the Spring (Full details in the next edition. Normal policy cover is available now).

Life Assurance There are two types of Term Insurance cover available, providing protection to meet your needs.

- **Level Term Assurance** – which provides a tax-free cash lump sum in the event of the death of the life assured during a specified period (the Term)
- **Decreasing Term Assurance** – sometimes known as a Mortgage Protection Plan, this policy is designed to pay off the outstanding amount of a repayment mortgage as it reduces over time, by clearing the remaining mortgage in the event of death within the term.

Household Insurance Insurance cover is available for buildings and contents, with a discount on the overall premium for insuring both the buildings and contents in a combined policy. Cover automatically includes new for old replacement of items, and the optional installment plan means that you can spread the cost of your premium.

Want a quote? Heath Lambert Affinity Partnerships have worked closely with the MG Association to gain a greater understanding of the reality of living with Myasthenia Gravis, not only for the individual but the effects that it has on those close to them.

Our staff are ready to take your call. For an immediate quotation call 01603 828359.

Insurance products and Financial Services are provided by Heath Lambert Consulting Ltd, regulated by the Financial Services Authority and is a member of the General Insurance Standards Council.

NB. Cover taken out via HLAP will result in a percentage of the premium being returned to MGA.



Region 12 - Karen Rynne Tel: 00353 65 6834444 Email: karen@mgauk-region-12.org.uk

Raising awareness is vital for MGA in Ireland. By organizing fundraising events I am spreading the word about MG, but in April 2002, I managed to persuade RTE's Nationwide to do a documentary on MG. It was a great success. I received phone calls from sufferers who never knew of the Association. They had been suffering alone for years. I have spoken on local radio stations and received many press releases. I am currently working with television stations, radio stations and national newspapers to get more national coverage. If you think you can help with any of these tasks in any way, I would be delighted to hear from you. The people of Ireland have a right to be informed of Myasthenia Gravis.

Since January 2002 I have organised many fundraising events, such as coffee mornings, auto fashion show (car show), bag packing in supermarkets, car wash, street collections, church gate collections, racecourse gate collection, Caribbean Beach Party (indoor), table quiz, shopping Centre collections, parachute jumping, James Bond Theme Night, Non-Uniform Days, Fashion Show, Discos and taken part in the Ladies Mini-Marathon in Dublin.

I am constantly organizing fundraising events and would appreciate if you have any fundraising ideas to give me or if you can help in any way. If you know of anyone who would like to take part in a parachute jump or the mini-marathon in June, please let me know. Funds are essential for us to carry out our 'research, care and education' programme in Ireland. I don't have a committee and my region consists of 12 counties in Ireland. Medical research is continuing every day to find a cure for Myasthenia Gravis; the researchers are depending on our fundraising to keep it going. The funds raised also help to cover the costs of the public and medical awareness campaign and also to support the MG branches across the country, which help to eliminate the isolation often felt by sufferers and their families.

**I am appealing for help in any way, however small.
If you can help, please contact me**

The Galway branch was set up in February 2000. This branch has been very successful in fundraising for MGA. Last year the Western Health Board funded the supply of the MG information video to every GP in that area. This speeds up the diagnosis of MG. Amongst other events, the Galway branch had 15 people skydiving in Offaly in September which raised almost €4000.

The Limerick Branch was set up in June 2002. It incorporates Counties Clare and Tipperary also. The Limerick Branch meets quarterly. In the next year there will be new branches in the South and South East of Ireland to cater for all other counties. For more information on branch meetings or new branches, please contact Karen (details above)

Raising Awareness:

In April 2002, RTE's Nationwide did a documentary on MG. It was filmed in Deirdre McComish's home in picturesque Brittas Bay, Wicklow. Deirdre is a Myasthenic and has suffered greatly in recent years. It was a great success. Raising awareness is vital for MGA and to do so we need funding. Every year I apply to various Trusts for funds to help with supplying the medical video, information leaflets and information packs in order to help sufferers and inform the medical profession. By organizing fundraising events I am also spreading the word about MG. I



Hampshire Branch On August Bank Holiday Monday we had a stall at the Stubbington Fayre and Donkey Derby. As always our stall was full of a variety of donated goods plus our tombola, and at the end of the day had made £109.51. With this being Jubilee Year, Fareham Lions who organised the show asked all stall holders if they would decorate their stall and dress if possible in red/white/blue. There would be a prize for the best dressed stall. Yes, you have guessed it! The MG stall was the winner and we were presented with a £50 cash prize by the Mayor of Fareham, Councillor Mrs Pamela Bryant, which made our day as you can see from the photo of Marge, e, Jodie and myself (Barbara Openshaw).



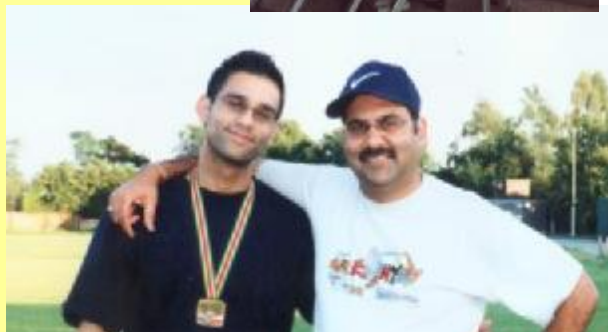
Region 13 - Rita Goldthorp Tel: 01980 626062 Email: rita@mgauk-region-13.org.uk

Despite the date change for the AGM our abseil off the Civic Centre went ahead as planned on Sat 21st September. The day was lovely and bright and the views from the rooftop were wonderful. The deputy Lord Mayor of Plymouth, Cllr. Bob Bellamy came along to wish everybody 'Good Luck' and our photo shows him shaking hands with Ian Munday from SpecSavers. Our next abseil in the South-West will be held on March 1st – St. David's Day and we therefore plan a

theme of Dragons and Daffodils – dress appropriately. All funds raised on this day will go to the new East Devon Branch of MGA.

You don't have to be super-fit (or mad) to fund raise for us in the South-West. If you feel that you would like to do something to help your charity then speak to Rita who will be able to give you some ideas for simple events in your area. We now have 7 branches meeting in the Southwest – The Devon and Cornwall Branch, based in the Plymouth area has until recently been working hard to cover the two counties. We have now, after a great deal of hard work, been able to set up The East Devon Branch to cover Exeter, Honiton, Seaton and Exmouth. Informal meetings are being held in Torquay, Cornwall (Bodmin), North Devon (Barnstaple) and Yeovil and District. The Somerset Branch still meets regularly in Taunton.

Ring Rita if you would like further details about any of these meetings or if you feel you can help with activities in the area. We are looking for volunteers in the South-West. If you can offer to help do anything from being the treasurer or secretary of a branch, placing collection boxes in shops, pubs and clubs, collecting in your local supermarket or street or just giving a lift to somebody so that they can attend a branch meeting, then I would love to hear from you.

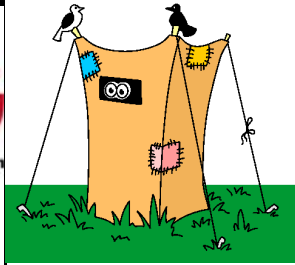


MG Flora Marathon 2002

Sunday 14th April 2002 was a great day as I (Omar Mughal) had completed the Flora Marathon in 4 hrs 34 mins in aid of MGA. My father, Magsood is a myasthenic (diagnosed July 91). We raised £250 from friends and family. Half of this was raised by my aunt, Mrs Zaida Awan and we send a big thank you to her. This is me and my dad and **MY MEDAL!**

Disability Living Allowance

There is an extremely good web site available on www.bhas.org.uk with links to many government organisations giving details, advice and help on completing the necessary claim forms for DLA.



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FULL Address,
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As shown below

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other companies, so please
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mg@mgaug.org.uk

Website: www.mgaug.org.uk

Registered Charity:

No. 1046443

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

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200 CLUB WINNERS

Draw Sept 2002

1st Mrs N Jenkinson, Walsall, W.Mids £60

2nd Mrs S Ward, Bournemouth £30

3rd Mr C Alexander, Forfar, Angus £15

Draw Oct 2002

1st Mrs A Colwell, Ashford, Kent £60

2nd Mrs D Andrews, Milton Keynes £30

3rd Dr EM McConnel, St. Asaph £15

Draw Nov 2002

1st Mrs M Shankland, Pontypool, Gwent £60

2nd Mrs R Fagg, Broadstairs, Kent £30

3rd Mr D Esson Jnr, Buckie, Banffs £15

*Please Note: The Draw months published in the last news letter were for
May, June and August. There was no July Draw.*

MGA New Years Draw

1st Prize **£1,000**

Please help to support your charity by purchasing or selling
the draw tickets enclosed. To avoid wasted postage, please
do not return unwanted tickets

LEGACIES

Thanks again from all at Myasthenia Gravis Association to the benefactors
who have remembered us in their wills.

Since the last MGA news we have received legacies from Kathleen Davies
and Elsie Makin. Our condolences go to their families and friends.

The financial support they have given makes a huge difference to the
ongoing work of Myasthenia Gravis Association.

If you would like to know how you can help with your will, please read the
red leaflet inserted into this newsletter.

Travelling through London? From the 17th February 2003, all vehicles coming into central
London will be subject to a fee (congestion charge). If you have a disabled person's badge
you will get a 100% discount (ie, free). If you are exempt from Vehicle Excise Duty (road
tax) you are automatically exempt and do not have to be registered with Transport For
London, however others do have to register.