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**MGA's 2002/2003  
Top Fund Raising Branch**

Regional Organiser, Steve Annable, presented the Charles Read Memorial Trophy to Chair of Leeds Branch, Heather Read.

The trophy is awarded each year to the Branch which raises the largest amount of money through fundraising. Leeds Branch raised an amazing £24,000.

Our grateful thanks to all those who have worked so hard on behalf of Myasthenics.

Some of the very hard working Branch members are shown here.



**There are 506,000,000 reasons why you should make the most of Tax-Effective giving**

**£506 million.** That is how much charities claimed from the Inland Revenue last year by taking advantage of tax-effective giving. Almost 70% of the population makes a regular donation to charity, but less than a quarter do so tax-effectively. That means that charities are missing out on millions of pounds of tax relief. Tax-effective giving will mean more for our charity at no extra cost to our donors.

**How does it work?** Anyone who has paid enough income tax or capital gains tax in the financial year of the donation which covers the tax amount reclaimed by MGA can use Gift Aid. For example, a donor giving £100 needs to have paid at least £28 in income tax or capital gains tax. If they have and they tell us they wish their donation (of whatever size) to be Gift Aided then, using the example of £100, MGA can claim the £28 back from the Inland Revenue, thus raising the value of a donation of £100 to £128 at no extra cost to the donor.

**What about Payroll Giving?**

When donors use Payroll Giving the donation comes from their salary before they are taxed, so tax relief is included in the donation at the donor's top rate of tax. So, a monthly gift of £20 will cost a basic rate taxpayer only £15.60 and a higher rate taxpayer only £12. In addition the Inland Revenue is currently adding 10% to every donation this way. So a £20 gross donation is worth £22 to MGA and only costs the giver £15.60.

**Who can use Payroll Giving?** Anyone paid through PAYE or receiving a company pension where the scheme is in use within their company - Why not ask them?



## Message from the MGA Chairman

Since I last wrote to you, Christmas has come and gone, and we are now well into a New Year. The work of MGA continues unabated. We have very limited resources and all the staff, and you - the volunteers and supporters - are having to work very hard to try to accomplish our objectives. One area of activity, which is central to our success, is our work to raise the awareness of Myasthenia Gravis, and our charity, amongst the public. A tremendous effort is going into this, and I believe that it should bear fruit this year. Without success in this area we have little chance of increasing our income, at a time when charitable fundraising is becoming increasingly competitive and difficult - and increasing our income is the key to doing more things we would like to do.

The Trustees of MGA continue to work hard on your behalf, and we have had two meetings since my last message. We have now approved the operating budget for 2004-2005, which provides for the continued operation of the charity along the lines you have seen in 2003-2004. In case you might believe that all the Trustees do is meet six times each year, I must tell you that the current Board is a very active group. In the last year we have set up three sub-committees - for medical research, finance and publications. All three of these sub-committees are now making important contributions to the work of the association. These activities involve the trustees putting in a lot of time and effort, for which I am grateful, both personally and on your behalf.

I am pleased to be able to tell you that, at the last board meeting, we appointed a new trustee to the board. Mr Malcolm Palmer retired from a successful legal career in 1993, having worked in UK and overseas, culminating with four years as managing partner of his firm. Malcolm continues to work for his professional institute; he is also a Special Tax

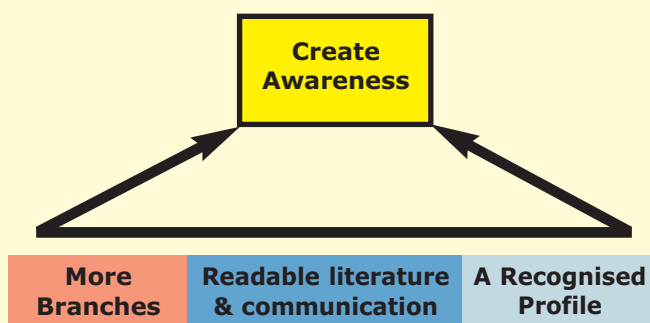
Commissioner and Chairman of a Tax Tribunal. In 2003 Malcolm was diagnosed with Myasthenia Gravis, and has since become an active member of the London (Central & North) Branch of MGA. We welcome Malcolm into the 'MGA family'. I am sure he is going to make an important contribution to our work.

*Peter Finney*  
Chairman of the MGA Board

## An Update from Alasdair Nimmo (CEO)

Hello everyone,

In the last edition I let you all know where we have directed our energies, by sharing with you the platform we have been building to create an overall awareness of our disease. As I said, with these three key pieces in place, the Association is now in a position to create awareness and start lobbying.



**Children In Need (Pudsey)** is supporting us in our attempt on a Simultaneous Low Impact Workout Guinness World Record. This will create much needed publicity both nationally and locally and in addition to this the Association will be co-ordinating a lobbying campaign to draw to the attention of MP's based in the House of Commons, the Welsh Assembly and in Scotland, Ireland and Government Departments that this Association is the only body creating education and information to support sufferers of MG.

So far so good - to date your Regional Organisers have been contacting their local fitness centres. We have had a full

page advert (at no cost) in the fitness magazine "Fit Pro", this has resulted in 40 interested instructors who appear to want to take up the challenge and join in. We anticipate that as a result of the Regional Organisers mailing lists that we will in fact be mailing to some 6,000 fitness clubs in the UK. So we are well on course on that front - asking clubs to take part. Perhaps you can help locally? Please let us know.

My thanks to all those of you who have offered your support in helping us to spread the gospel with our Press Release. We have had offers of help from those who wish to approach local newspapers, to those who are involved with websites managed by the BBC and we would like to say a BIG Thank You to them.

If you want to become involved in the event then please contact your Regional Organiser who has more information.



**Watch out for Pudsey Bear and our Low Impact Workout in your area. The date to earmark is Friday 19th November 2004**

Sadly as we go to print we have lost the services of the Regional Organisers for Scotland and Anglia. We wish both Louise and Steve well in their new chosen careers. I am pleased to advise those members in Scotland that we have recruited a replacement for Louise: Michael Heaps who will be in contact with you in due course. We are currently interviewing to replace Steve's position.

Once again thank you for all your support.

*Kind regards to you all*  
Alasdair Nimmo, CEO

## MGA Publications

### New Developments and a **Plea for Help**

Just over a year ago, the Board formed a Publications Sub-Committee to continue updating our literature. The Committee Members are:

Mr Rodney Haverson, Trustee (Chairman)

Mr Alasdair Nimmo CEO

Dr David Hilton-Jones, FRCP, Neurologist (Oxford)

Prof Nick Willcox, Trustee

We were also lucky enough to be able to call upon a panel of experts from the various medical disciplines caring for Myasthenic patients.

Collectively, we have some know-how about producing information literature but we cannot cover all the topics we have identified, **so we need help from you.** The MGA is your Association. For example, we would be extremely grateful for any subjects you would like to be included in:-

### **Volume 3**

Dealing with complementary treatments

### **Volume 4**

Focussing on benefits and services available to patients.

For Volume 4, we particularly need offers of help from anyone with experience in the DWP, DSS, DVLA, Social Services etc. If you could draft something in these areas (however roughly), we would be happy to 'ghost-write' and format it, before asking you to double-check the near-final version.

We have already completed:-

1. 'Facts about MG (for the beginner)'
2. Info Pack Vol 1 'MG for the new patient'
3. Info Pack Vol 2 'Congenital myasthenia and the LEMS'
4. 'Dentistry and MG' (already included in Vol 2 and will be included in the next revision of Vol 1)



(continued from page 3)

We are currently working on:-

### **Info Pack Vol 5 'Medical Information'**

All the myasthenias (for professionals and carers)

### **Info Pack Vol 6**

A collection of articles from MGA News

We have had Volume 1 appraised by the Centre for Health Information Quality; its valuable suggestions have been followed in our fine-tuning of Volumes 2 and 5.

*"... so we do need help from you.  
The MGA is your Association"*

Even more importantly - as they are meant for you - we would welcome any feedback from yourselves. Do you have any thoughts on what topics still need to be included?

We are also working on new developments and specialist information on:-

MG and the Optician/Optomtrist;  
MG and the Speech therapist;  
Myasthenias in childhood.

Again, suggestions for anything that you think we should add will be most welcome and should be sent to the Chairman of the Publications Sub-Committee, at our support office in Derby (address on back page).

**Many thanks for all your input.**

## **Information that is helpful to schools looking after children with myasthenia**



### **Flexible arrangements that can be helpful**

Having a chair to sit on instead of having to get down and up from the floor

Having flexibility about starting times and attendance and not getting hassle about being late or absent

Being able to stay indoors during playtime (having the choice about whether to go out)

Having the choice about the level of participation in PE lessons, and the opportunity to opt out

Having the optimum time to eat dinner and being able to have a drink with the meal

Having extra time for completing written work, this being relevant particularly during exams and assessments

Not being made to stand in queues

Explaining to the class, with the agreement of the pupil, what Myasthenia is and how it might affect their class mate

### **Points of consideration for class teacher**

It may be difficult for the child to put their hand up. Is there another way they can indicate an answer or ask for attention

The pupil may need to put their head on the desk as they may be using it for support

The pupil may have difficulty reading aloud due to weakness in the voice

The pupils fine motor skills may deteriorate with weakness and help with recording work may be required

***The opportunity to communicate with school on a daily basis is important so both home and school have a current understanding of the child's level of weakness and level of need***

### **How to live a happy life...** by GEORGE CARLIN

1. Throw out non-essential numbers (Age, weight and height). Let the doctor worry about them. That is what they are there for.
2. Keep only cheerful friends. The grouches only pull you down.
3. Keep learning. Learn more about the computer, crafts, gardening, whatever. Avoid an idle brain - that is the Devil's workshop and his name is Alzheimer.
4. Enjoy the simple things.
5. Laugh often, long and loud. Laugh until you gasp for breath.
6. Tears happen. Endure, grieve and move on. The only person with us our entire life is ourselves.

7. Be ALIVE while you are alive.
8. Cherish your health. If it is good preserve it. If it is unstable, improve it. If it is beyond what you can do, get help.
9. Don't take guilt trips. Take a trip to the shops, the next county, a foreign country but NOT to where the guilt is.
10. Tell the people you love that you love them at every opportunity.

**AND ALWAYS REMEMBER . . . life is not measured by the number of breaths we take, but by the moments that take our breath away.**

## Edward Lambert (1915-2003) of the LEMS

(Lambert Eaton Myasthenic Syndrome)

*Professor Nick Willcox writes:*

Sadly, our beloved colleague, Professor Ed Lambert, died in Rochester, Minnesota, last July. For fifty years he had been a universally acknowledged expert on **electromyography** (EMG). We are especially grateful to him for recognising the distinction between MG and the LEMS in a classic report in 1956 with his Neurologist colleagues.

Born in Minneapolis, Ed Lambert grew up in Chicago, where he qualified as a doctor in about 1939. Soon afterwards, he did a PhD on the effects of oxygen and carbon dioxide on blood flow and heart function. He was then head-hunted by the Mayo clinic in 1943. Very interestingly, he was to work on the blackouts that fighter pilots got when subjected to strong G-forces. He himself was often used as a guinea pig, and blacked out 23 times.

Mercifully, that seemed not to have damaged his brain.

As in so many other fields, war accelerated advances in physiology too. Ed's own vital contributions included devices for monitoring blood pressure and simple tricks that the pilots could practise to prevent or limit their blackouts, some of them are still used today. The work culminated in the development of pressure suits (like those seen on films and TV); also in a Presidential Certificate of Merit for Ed himself in 1947.

He maintained these interests into the 1960s, but, after the war, he turned his mind mainly to EMG, which was still in its infancy. He was in the right place at the right time; the Mayo Clinic's Neurology centre was then, and still is, one of the foremost in the world. It now also has great strengths in the inherited myasthenias as well as MG, partly thanks to Ed's expertise. In 1955-6, his colleague Dr Lee Eaton became interested in some unusual myasthenic patients with lung cancers (which, as we now know, are

found only in around half of LEMS cases). It was Ed who noticed several key differences in the EMG, and in muscle 'ignition', in this syndrome soon to be named after them. Most important was his evidence of reduced release -

from the nerve endings - of the transmitter (ACh; 'ignition key'). Typically also, the patients get stronger as they try harder (unlike in MG). It eventually turned out (in 1981) that the weakness is caused by an immune attack on the nerve endings. That was first shown by Dr Bethan Lang in Prof John Newsom-Davis' team - which is ironic, because Ed Lambert's wife, Dr Vanda Lennon, had crucially helped to show the same kind of explanation for MG back in 1973.

Ed did not rest on his laurels, which included Lifetime Achievement Awards from the American EMG Association among many others. He continued doing pioneering work on EMG methods, on neuropathies (eg in diabetes and carpal tunnel syndrome), on motor neuron disease and on muscle disorders, including Lambert-Brody myopathy. Ed was renowned for his determination and stamina; indeed, he continued working until over 80. Having two syndromes named after him shows how widely respected and loved he was. He was also the most gentle and unassuming of characters. He was a great teacher too, and many of his trainees have done extremely well. He is greatly missed; it seems fitting to remember Isaac Newton's words (1676):

***"If I have seen further, it is by standing on the shoulders of giants"***

*We are grateful to The American Association of Electrodiagnostic Medicine for permission to reproduce the photograph of Dr. Lambert.*

*You can read further details about Dr Lambert, on-line at their site at*

*[www.aaem.net/aaem/news/DrLambert.cfm](http://www.aaem.net/aaem/news/DrLambert.cfm)*



**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 MGA,

Some years ago I was driving my car when I lost all power and was able to slowly glide to rest at the side of the road. The garage mechanic said it was because the leads to the car battery had become disconnected- therefore no power. My having myasthenia gravis seems to be just like that - no power! I can put my foot on the accelerator but it brings no response. My MG was diagnosed 5 years ago when I had reached crisis point aged 78. Marvellous neurological treatment, medication, etc have enabled me to live at home. Friends and family too are very supportive and I don't (at 82) have an active family dependant on me any longer. I find the newsletter with information on research into this condition very interesting and encouraging.

Your sincerely,

CHRISTINE FRANCIS, Berkhamsted

Dear Feedback,

My name is John, I was diagnosed with MG in June 2003. I started with double vision at the end of May that year and within two months was experiencing extreme weakness all over my body and was having to use crutches to move about. On 22nd July I kept my appointment with the neurologist at Scarborough hospital, who immediately told me I had to be admitted to hospital and was taken directly to Hull Royal Infirmary as an emergency admission. During the following three weeks, the doctors on Ward 12 tried all the usual treatments including five day of IG infusion - to no avail. My condition continued to deteriorate, so I was transferred to Castle Hill hospital for a thymectomy. All of this time I was unable to walk or do anything for myself. My swallowing was non-existent and my grip was so bad I couldn't even hold a pen to do any writing. Even the consent form for the

operation had to be signed by a nurse. The thymectomy went well and immediately on waking up in the ward, I found I could move my eyes and a small amount of strength had returned to my limbs. I spent a week at Castle Hill before returning to HRI where I stayed for another four weeks. After discharge, I continued to make small improvements through September and the first part of October until I picked up a head cold which caused a relapse and I was rushed back to Hull with extreme breathing and swallowing problems. I spent a week in the High Dependency Unit at HRI where I had three attacks of not being able to breath.

The doctors gave me doses of Neostigmine and Atropine IV to kick start my respiratory muscles and gave me injections of hyociene to dry up secretions in my airways, because I was unable to cough to clear them. I was then transferred back to Ward 12 where I spent another two weeks. My condition improved tremendously during that time, but I still had swallowing problems. The doctors were worried about me contracting aspiration pneumonia after conducting tests which showed a small amount of food and fluids passing into the airways, but thankfully the swallowing slowly improved and I was discharged at the end of November. I have since come on in leaps and bounds and apart from weakness in my lower legs, my strength is practically back to normal. The medication I am on is 120mg Pyridostigmine, six times daily and Azathioprine 100mg daily. Prior to the start of the illness I was a very fit long distance cyclist which I think helped me through the illness. My muscle bulk is slowly returning. I still walk with one crutch if I go any distance. I'm told the condition can take up to two years to go down and go into remission but I'm in no rush because I've got some quality of life back. I have had good support from all the

medical profession and I am very grateful to the staff at Hull Royal Infirmary who did a wonderful job in getting me back on my feet. I hope this letter is an inspiration to other newly diagnosed MG patients and shows what can be achieved if you have the willpower.

Yours sincerely

JOHN CLARKE, Scarborough

Dear MGA News Editor,

Most people heard of the tragic bus crash in South Africa on New Year's eve. It was only later that we found out that our member, Marion Moon and her husband Steve had lost their lives there. Marion was an active supporter of the MGA, first in the SE London/Kent Branch and later in the Kent Branch. She helped to raise funds by events in her area, particularly at the riding school. She also wrote of her travels and showed slides for the branches. Despite her MG and Steve's recent illness, she was not deterred from holidaying in unusual places. She walked in Japan, explored in Iceland and Greenland and in many parts of the world the rest of us only dream of.

Marion and Steve were a very talented couple. They re-designed their house and garden with style and taste that would be envied by today's TV make-over programmes. We appreciated the garden parties she held. Marion and Steve will be missed by us all. We offer our sympathy to Marion's parents, Mr and Mrs Bishop who have themselves attended some of our meetings and to both families as they grieve the loss of two lovely people.

JOYCE AND NORMAN BLADES, SE London Branch.

Dear MGA,

I read with interest your information on Mestinon Prolonged Release. It was thanks to your previous information that I have now been prescribed these tablets. Neither my GP, Pharmacist or Consultant had heard of them and there is no information about the prolonged release tablets in the September 2003 BNF (British National Formulary). Thanks to a helpful GP and Pharmacist and an agreeable Consultant, I have been allowed to try the medication rather than go onto steroids, as the next course of action.

Getting up in the night to take additional Mestinon wasn't very practical for myself as a shift worker and having to eat a small meal. The ordinary 60mg Mestinon gave me fairly powerful side-effects - nausea, retching, sometimes severe stomach cramps leading to diarrhoea. I wondered if the slow release would be gentler. I under-dosed for the first 3 weeks - 1x180mg breakfast and supper. Now it is 1.5 morning, 60mg as a boost at 5.30pm and 1 tablet 9.30pm. You can halve, but not quarter the tablets and I find the daytime dose lasts 8-9 hours. I may have to adjust it again but I'd rather under-dose then overdose. I am much less likely to get muscle cramps at night, to feel severe nausea in the morning or to have diarrhoea. I also don't have to eat so much with each intake. I am aware that some of your readers are on far more powerful medication, eg steroids, and far more Mestinon.

However, I would like to pass on the fact that, for myself, the quality of my life has improved due to the reduction of side-effects and less weakness on waking. I am happy to pass on anecdotal evidence to medical staff who may wish to study the effects of Mestinon Prolonged Release. Despite my enthusiasm for these new tablets, I endorse your comments that patients must ask their consultant's advice based on their own particular circumstances.

Yours sincerely,

FIONA RENDALL, Shetland

Dear Editor,

Just like Julie Lee, who wrote in the summer of 2003, I find it difficult to continue doing my job to the best of my ability. I was diagnosed in May 2002 and though much improved, I have accepted that I cannot work the hours I used to and I am now working 6-hour days for the foreseeable future. I am a serving Police Officer with Devon & Cornwall constabulary and I am the only known case.

I would dearly love to hear from any serving officer with MG or anyone who had to retire from the police because of MG.

Yours sincerely,

LYN EDWARDS, Newton Abbot



## Harry Noah Shorrick

Harry Shorrick was the highly esteemed Chairman of the Newcastle Branch of MGA who sadly passed away on 4th February 2004. He was diagnosed with MG in September 2001 and being the kind of person he was, he immediately contacted Head Office for information and to see if there was anything he could do to help. He set up the Newcastle Branch in December 2001 and held the inaugural meeting in his house in March 2002 and from that the Branch was formed.

Harry will be sadly missed by his wife, Sheila, his family and his friends.

JEAN FLETCHER, Newcastle Branch

## Sylvia Elliston (née Bates)

Sadly, Harry Elliston wrote to notify us of the death of his wife, Sylvia who passed away in Truro on February 2nd 2004.

Sylvia was known the world over for corresponding with other sufferers and was at one time treated by Dr Mary Walker and Prof. Newsom-Davis. A picture of Harry and Sylvia appeared on p4 of the Winter 2002/3 Newsletter.

*Ed*

## Clive Finch

Until ill health made it difficult for him to continue, Clive Finch was Treasurer of the Berkshire Branch. He was diagnosed with MG in 1990, shortly after he retired from a highly successful commercial and academic career in catering. This made him very tired and quite weak, but it was under control and he managed to carry on with most of his activities. Then he had a stroke five years ago, and had to start taking things more easily, continuing with some of his hobbies but not so energetically. Because of his now limited mobility, he started to use an electric scooter and, typically, wrote an enthusiastic account of taking it abroad on holiday for the Berkshire Branch Newsletter. Sadly, his health continued to decline, and he spent much of last year recovering from major heart surgery. Finally, he collapsed with a brain haemorrhage, and died peacefully in his sleep in High Wycombe Hospital.

He was a man of great spirit, warm hearted and talented, remembered with affection but sadly missed by all who had the privilege of knowing him. Yet, even at his funeral service, Clive's mischievous sense of humour came through. He requested that the 1812 overture be played so that he 'could go out with a bang'.

ROBERT CRAY, Berkshire Branch

## Pamela Homard

It is with sadness I write to say that Pamela passed away on 23rd February 2004. She had suffered with Myasthenia Gravis for many years along with other illnesses.

Pamela and husband Freddie have been long and loyal members of our branch for many years, with Freddie serving on the committee for a time. She will be sadly missed.

We send our sincere condolences to Freddie and his family.

BARBARA OPENSHAW  
Hampshire Branch

## Alice Mercer

It is with great regret that we have to announce the death of Mrs. Alice Mercer, a member of the Wigan Branch.

Alice was a wonderful lady who will be sadly missed by all her friends at the Wigan Branch. Our thoughts and prayers go out to her husband William, daughter Pam and all her family.

ALISON LEE  
Wigan Branch





Kevin Blackery presents a cheque for £708 to **Beth Elston, treasurer of the Leicester and Rutland Branch.**

Kevin is the retiring Provincial Grand Primo for the Nuneaton Province of RAOB. He chose MGA as his charity for his year in office as his wife, Jane is a myasthenic. The money was raised by various means including a sealed auction for a football signed by all players of Manchester United Football Club.



**Pam Evans of Swansea Branch** sends this photo of the Patti Pavillion Charity Fair in November

which raised £190. Additional funds were also raised at the Coffee Morning (£100) and at the Cwmtawe Comp School (£615). They have also obtained sponsorship of £400 to help towards the cost of transport to the Medical Conference in April.



On 20th September 2003 at our **Merseyside MGA, Fred and Muriel Parry** announced that they were retiring as

committee members from the Merseyside branch. As well as being founder members of the Branch, they had worked tirelessly to raise funds, arrange concerts and, assisted by their family, had ran a "Warrington Awareness Day" stall for many years. The Committee organised a presentation afternoon to acknowledge the twenty plus years of voluntary work for the branch. They were presented with inscribed, fluted, champagne glasses (and of course a bottle of champagne).

**Newcastle Branch** are holding a Coffee Morning in the Lord Mayor's Mansion House on Thursday 3rd June 2004. If this is something you would be interested in, then why not give Jean Fletcher a call on 0191 2371355

**South Wales Branch** would like to thank Herefordshire Caravan Club for making MGA their annual charity for the year 2003. We are most grateful for the donation of £750 forwarded to our branch from Mrs Wilce (South Wales Branch member) and Mrs Coombes (Herefordshire Caravan Club). Such thoughtful donations greatly assist the MGA to continue in their work of raising awareness, providing information and local group support and also help with the ongoing research programmes. Thanks from all in the South Wales Branch.

GORDON WEBSTER (Branch Secretary) and DENNIS AMOR (Branch Chair)

**North of Scotland Branch** reports that they have been lucky enough to receive a grant of £500 from Aberdeen Students' Charities Campaign to help them in sending videos to GPs and Opticians.

### CLINICAL STUDY

A clinical study in MG will be starting soon in the UK. This will investigate a new immunosuppressive drug (Mycophenolate mofetil) for the treatment of more severe forms of MG (non-ocular). We hope to have more details in the Summer Newsletter.

**Merseyside Branch** sent a photograph of Eileen Evans at a stall in Ormskirk market, Merseyside during the festive



season. She also has a table, one morning a week, to sell her hand-made cards at the Walton Neurological Centre hospital, here in Liverpool, to raise money for the association. Over the Christmas period she raised approximately £150 by selling her beautiful cards. Eileen was diagnosed as having MG in 1992 and has raised money in various ways.





**Bradford based PUBLICO**, selected the Myasthenia Gravis Association's West Yorkshire support groups as their charity of the Year for 2004/5.

**Chief Executive, Allan Harper said:**

"As a community conscious and progressive company, we wanted to support a local charity and decided on Myasthenia Gravis as they have branches offering support to sufferers within the location of all of our outlets."

**MGA Regional Organiser** for Yorkshire, Steve Annable explained to them, "The disease affects the receptors between the nerve endings and the muscle. You can be fine in the morning but by afternoon you could have drooping eyelids, double vision, slurred speech and be unable to walk or breathe properly. The disease has no known cure and can prove fatal. One of our best known snooker players, ex World Champion, John Spencer had to retire from playing due to MG."

**A Full Programme** of events is being put together for all the West Yorkshire pubs with a target of £100,000 for the year.

**Operations Manager for PUBLICO, Paul Crompton** says: "We are delighted to join forces this way and look forward to offering our customers another reason to visit their local pub this year. We are currently installing exciting Entertainer systems into fifty of our pubs which we can utilise to raise money and we are hoping to put on Bungee Jumps and even Fire Walks, plus lots more to help swell fundraising."

**Over the Easter Weekend** we have Bungee Jumps planned at three pubs in Bradford and one in Halifax.

To find out more on these events or if you wish to help with fundraising call:

**Steve Annable on 01457 766410**

## The MGA Needs You

*Good news! The MGA is aiming to combat the nation's ignorance of Myasthenia Gravis.*

- We are planning to start a new Education Project to spread knowledge of MG more widely across the UK
- We would like to give more talks in clubs, schools and businesses, so that the problems and needs of people with MG are better understood by the population at large
- We need your help to get this national project started
- Are you brave and articulate enough to help our members by telling others the truth about MG?
- Can you help us cover the whole of the UK by offering to give a couple of talks in your local area?
- This is a unique opportunity to tell people what having Myasthenia is all about.
- We will provide full training and materials to help volunteers to get our message across.

**Please help us!  
Contact Phil Rossall on  
01689 605626**

You may find the following MGA Web Sites of interest:

**Our Main Site**

<http://www.mgauk.org.uk>

**Our Events Site**

<http://www.mga-charity.org/events>

**Our Children In Need Site**

<http://www.mga-charity.org/cin>

**Our Donation Site**

<http://www.justgiving.com/mga/raisemoney>

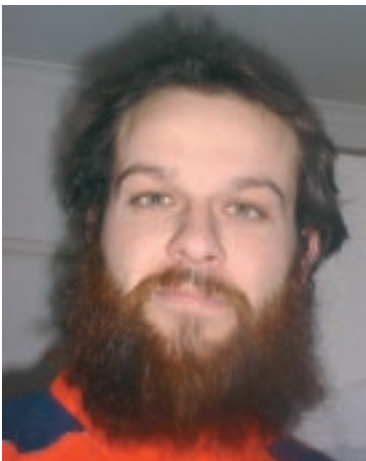
**Or to make a Donation:**

<http://www.justgiving.com/mga/donate>

## Gavin's Beard



**Before and present day**



Gavin Stone, an Archaeologist started the **mammoth** task of growing a beard to raise money for MGA.

Gavin's mum, Pat Stone from the Isle of Wight has MG.

At the time of going to print, Gavin had over 1700 visitors, £400 worth of donations and has even had a five minute slot on Steve Wright's Radio 2 program as Website of the Day.

Gavin is doing this to help you and hundreds of others who have been diagnosed with Myasthenia Gravis. Companies who have an interest in Hair and Beards

may be interested in the Big Shave Day to promote their products and raise money for MGA at the same time. Why not visit his site at <http://www.beardforcharity.org.uk> and give him some support or alternatively contact Lynne Pitcher, publicity officer, IOW Branch on 01983 761265 who says she is happily married to a guy who also has a beard. If you are able to sponsor his beard growing or know of a company that is able to sponsor him, then please contact Lynne.

## Ally Carruth and Mike McRitchie Report back from the New York Marathon, 2nd November 2003



As veterans of one marathon, completed in just under four hours (which, while not record breaking, is not too bad either), we decided this time to complete it in drag.

We set out for New York on the 30th October. Once there, the usual tourist activities were completed, not to mention a 'maiden' airing of our dresses and wigs on Halloween, where we found ourselves caught up on the metro surrounded by dozens of people dressed as vampires, ghosts, monsters and, bizarrely, in one case, a salad!

The day of the marathon came and on arrival on Staten Island we found the longest queue in the world for toilets and it was fortunate that the site also boasted the Official World's Longest Urinal. The race snaked its way through Brooklyn then on into Queens, up 1st Avenue into Manhattan onto the Bronx which took us to the last four miles.

We loped through Central Park, past the countdown signs to the crossing line. This brought extreme tiredness, a sense of accomplishment, and yes, more vomiting. The weather was unseasonably warm with temperatures in the 70's and humidity around 85%. We had just run 26 miles in costume, whilst raising money for a worthy cause and in so doing attracted much attention, but we probably still came across as just a pair of British chumps in dresses.

However, more importantly, we drew the attention of hundreds of thousands of spectators to the MG Association.



This is a photo of Sister Beesley and myself along with other colleagues on the Endoscopy Unit at Stoke Manderville Hospital, Aylesbury. We decided to collect money this year instead of sending each other Christmas cards. Thanks to the generous bunch I work with, we raised £150 for MGA

*Wendy MacKnight*





### Lancashire Branch Chair, Martin Haworth

receives a cheque from Anne Smith as a donation from her stand up comedy routine entitled "Fat Lass with Stick". - Anne has MG.



**Graham Littler** supported **Leeds Branch** again raising over £600 in the Great North Run and £670 was also raised from table top sales thanks to Joan McLean and her team. A team from North Wales completed the London to Paris Bike Ride Challenge and raised £1,500 - thanks to Dyfed and Dafydd Whiteside Thomas. £250 was received to support the Cheshire area from Grand Lodge of Cheshire Freemasons.

**South Yorkshire Branch** have £500 donated from Bawtry Lodge of the Masons for medical videos to be distributed to GPs and Opticians in the Doncaster area - a big thank you to Keith Bennett.



**Glossop Central Methodist Church** raised £310 through a Christmas Card Board Promotion - many thanks to Jenny Cooper and all at the church.



**An Abseil** at Manchester's Velodrome raised £5,000 in November. Warrington Branch Secretary, Kim Bunting dressed up as a Rag Doll and Sonja Leggett raised an amazing £1,250. Picture shows some of the abseilers, Tim Bennett from Pontefract and Paul Williamson from Bolton. Also taking part were Representatives from branches in North & South Manchester, Wigan & Huddersfield. If you are interested in next year's event contact Steve Annable - 01457 766410.

**Eike Friedrich's** Great North Run was supported by **Tyne Tees Branch** who raised over £100 - thanks to Beryl Watson and all at the branch.



**Legal & General** in Manchester held a dress down day for our Manchester Branches raising £400 - thanks to Cath Williamson from North Manchester Branch for her help. Standard Life also made a donation of £30. Cath and husband Paul already run North Manchester's Ebay Auction site at:

**<http://members.ebay.co.uk/aboutme/mgafundraiser/>**

and have raised over **£1,000** to date - well done Cath & Paul. Picture shows Steve Annable with John Hulme from Legal & General & Cath Williamson.

*(Ed, watch out for word wrap on the above internet link. It needs to be all on one line.)*



A great deal has happened in this Region since the last edition of MGA News. The **London South-East Branch** has succeeded in being adopted as the official Charity

of the Year by the Bromley NHS Trust and several local schools. **Belvedere Junior School** has just sent us the first batch of sponsor money for their Christmas concert, which was over £150. Other activities - including a coffee morning at Branch Secretary Anna Martin's house, Sainsbury's Penny Back scheme.

A parachute jump by Sixth Form students from Darrick Wood School, Orpington - have brought in another £2,000. Pictured are two students from the school.



We had some excellent publicity in the **Richmond Branch** area, following the decision of

the Twickenham company, Edmundson Electrical, to hold their Christmas raffle in aid of the MGA. Michelle Driver and her husband Steve brought their daughter Hollie (who has CMS) to help make the draw and gave an interview to the local newspaper, which attracted a great deal of attention. Pat Dawson of Edmundson's then handed over cheques totalling £1,400.

**Croydon Branch** member Padraig Kelly took part in the Woking abseil and raised £250



for MG. Rotary Club and Round Table talks in the area have also been very productive and have led so far to donations totalling over £1,700.

The Branch has been busy organising events, such as a recent visit to Parliament. Pictured right is part of the group, including Branch Chairman Alex Clark and Treasurer Derek Scrafton. They have upcoming trips to Kew Gardens and a summer Garden Party. For details, please contact Branch Secretary Dianne Ranasinghe.

The Branch has also completed its purchase of MG videos for GP's and opticians in the whole of its area, using funds it raised from



a series of successful events. Pictured left is Branch Treasurer Derek Scrafton handing over a copy of the video to Dr James Gillgrass of the Birdhurst Surgery in Croydon.



**London (SE) Branch Chairman Phil Warn** (second from right) receiving a cheque

for £400 from the manager of Sainsbury's, Locksbottom, Kent.

## A MARATHON TASK FOR ME!

- I have entered for my FIRST Marathon
- This takes place on 16th May 2004
- The venue is Halstead, Essex
- Please pledge some money to make the effort worthwhile and to make sure I don't Chicken Out!
- Call me on my number above
- Many, many thanks

*Phil Rossall*



Michelle Fetherston from Blanchardstown in Dublin organised a fundraising disco in October '03 and raised over €2000 for the MGA. Well done Michelle! Thanks to Michelle's

parents and friends who helped organise the event. Michelle, who has MG, was also interviewed with Karen Rynne on TV3's 'Ireland AM' which created much needed public awareness for MG and MGA.



Michelle is pictured presenting the cheque to Karen Rynne

In July '03, Stanley Way from the Myasthenia Gravis Foundation of America visited Ireland. During his travels he met

with the Belfast & Galway Branches and before his departure he met Karen Rynne. Stanley was delighted to meet Irish myasthenics and exchanged literature and memorabilia with the MGA members. **Susan Fahy, Chairperson for the Galway Branch**, was on holiday in Maryland the following August and while there, she met the MG branch from Maryland/Washington. Pictured are members of the Maryland/Washington MGFA Branch. Susan is second from the right.



**HEATH LAMBERT INSURANCE**

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

**Travel Insurance Offer from HLAP**

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

They are also able to offer a highly competitive Single Trip product with a comparable range of attractive benefits. Winter sports can be included under both options.

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

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

**HLAP can be contacted on 01603 828359**

**SUBMISSIONS TO THE NEWSLETTER**



Please submit articles and photographs well before copy deadline date where possible. Edition deadlines are for guidance only. The printer's resources often dictate the actual deadline. Please endorse the reverse of each photograph with a caption and date and include names and locations. If you wish photos returned please indicate on the reverse and give the address they should be sent to. However, there are NO guarantees as photographs pass out of our hands during the publication process. Published articles/letters may be shortened and/or changed to accommodate available space and editorial constraints/policy.

Edition	Copy Needed by Date
Summer 2004	14th May
Autumn 2004	6th August
Winter 2004	12th November
Spring 2005	11th February



Region 13 — RITA GOLDTHORP — Tel: 01980 626062

E-mail: rita@mgauk-region-13.org.uk

### Recycling of printer cartridges and mobile telephones.

We have organised a scheme to raise funds from the recycling of the above items - raising funds without the work!

All you need to do is simply telephone or e-mail Rita and ask for a recycling envelope. Once you send off your cartridge, you can ask for a further supply to be sent directly to you. We will receive £1 per cartridge and £1.50 - £40 per telephone.

**Sponsored Bulb Planting.** We had an excellent result last year from our bulb planting event held mainly in Cornish schools. A fantastic sum of £795 was raised by 5 schools- well done to you all. This year we hope to extend the scheme to Devon and Dorset so do get in touch if you know of a group of people who would like to work with us. We supply the bulbs and ask local youth groups to plant them in the towns and villages or on school premises. The idea is to

improve the local area whilst raising sponsorship for MGA to use locally.

### Dunster and Gillingham and Shaftesbury Shows.

The Yeovil and District branch hope to have a stand at these two shows during August and would appreciate donations of unwanted gifts or bric-a-brac. Contact Rita who can collect items at branch meetings.

**The Horseless Team Event** to be held on the Badminton Estate on Sunday 3rd October 2004. This will be our major fundraiser for MGA in the Southwest this year and we hope that many of you will be able to persuade friends and family to take part, or just come along and enjoy the day.

**This annual event** organised by The Rotary Club of the South Cotswolds has chosen MGA as one of the beneficiaries this year. We expect to benefit from around £4,000 and you can help us to increase this by asking teams to take part on our behalf and raise sponsorship. Information packs will be available from Rita.

## Department of Works and Pensions

Rita Goldthorp (RO) recently attended a meeting in North Devon where they were very fortunate to have a speaker come along from the Department of Works and Pensions. It was surprising just how little was known about this subject and a few points were raised which she considers are well worth passing on.

1. Do remember that if you have given up work because of your MG (or any other serious illness) that you should check on benefits such as Disabled Living Allowance (DLA).
2. If you are over 65 then you need to ask for details of Attendance Allowance. Don't listen to people who tell you that MG is not a disability and that you cannot claim!
3. Think about your daily routine. Who has to strain the vegetables because your hands and wrists are too weak to hold the pan? How often do you arrive at your destination and then decide you cannot

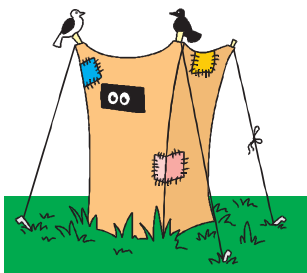
continue because you are unable to park near enough to walk? How often do you need somebody to sit with you whilst you eat in case you start to choke?

4. If you are in receipt of benefits you should automatically be receiving pension credits towards your retirement (not to be confused with the new benefit called Pension Credits). If you are not claiming benefits, then do go along and 'sign-on' otherwise you will get to pension age and find that there is nothing in the pot.

5. Blue Badges are always a problem for people with MG but it is another area where you should be entitled to receive one. Ignore any initial letter turning you down and appeal. The key thing to remember with all of these applications is to complete the form describing how you feel on your worst days - do not confuse the issue by putting 'on a good day...' etc. The questions relate to how bad you are.

**Why not ask somebody from the DWP to come along to one of your meetings?**





## Don't Hide – SUPPORT YOUR CHARITY

### Research Care Education

Please quote our  
FULL Address  
**including our name**  
in all correspondence  
as shown below.

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

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

Tel: 01332 290219  
Fax: 01332 293641  
Email: mg@mgauk.org.uk  
Helplines:  
UK 0800 919922  
Ireland 1800 409672  
Website: www.mgauk.org.uk  
Registered Charity No: 1046443

**We're on the WEB**  
[www.mgauk.org.uk](http://www.mgauk.org.uk)

The Association does its  
best to ensure that the  
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the time of publication,  
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## 200 CLUB WINNERS

### Draw November 2003

**1st: MRS. S. WARREN, Luton, Beds. – £60**  
**2nd: MR. W. BAXTER, Dundee, Tayside – £30**  
**3rd: MR. SMALLBONE, Kent – £15**

### Draw December 2003

**1st: MRS. E. LAWRENCE, Louth, Lincs. – £60**  
**2nd: MR. W. J. WILLEARD, Kent – £30**  
**3rd: DR. H. E. MATHIAS, Southampton – £15**

### Draw January 2004

**1st: MRS. P. COLLETT, Tynemouth – £60**  
**2nd: MR. J. E. CLEMENTS, Surrey – £30**  
**3rd: MRS. J. R. BANFIELD, Suffolk – £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 2004**

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

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

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

I will pay by: 1. Monthly Cheque/Postal Order (payable 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 2004.