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Beautiful Healthy Baby Born on Leap Year Day

Nicole Elizabeth Hales was born on leap year day (29th February) to Caroline Hales. Caroline has suffered from Myasthenia since she was eighteen and underwent a thymectomy at the age of twenty under Dr Hilton-Jones at Oxford.

Caroline also holds down a full time job in the IT department of a large Insurance Company and had a trouble-free pregnancy from day one —working up until one month before Nicole was born. She is coping well with her myasthenia and with motherhood. Proud dad, Paul looks on.

The down side of being born on February 29th is that poor Nicole only gets a birthday every four years – the upside is that she only ages a quarter as fast as the rest of us!

However mum and dad have promised to celebrate her birthday every year on 1st March just so that Nicole doesn't miss out on her presents.

Tax - Self-Assessment Returns

This year, for the first time, you can donate all or part of your tax repayment to a charity of your choice. Here's how:

- Tell the Inland Revenue how much you want to give. If you want to give all of the repayment then tick box 19A.1. If you want to specify a maximum amount then enter that in box 19A.2.
- Choose your Charity and enter their Code Ref in box 19A.3. (MGA's code is KAC72JG).
- For Gift Aid to apply on this, then tick box 19A.4. This will mean that your charity will get an extra 28% from the Inland Revenue helping your donation go further and without costing you any more money.
- Your donation will be anonymous unless you tell the Inland Revenue that they can give your details to MGA. To do this tick box 19A.5.

MGA's 10th Annual General Meeting

Diary Note: Please make a note in your diary that the 10th Annual General Meeting will take place at Leeds Town Hall on Saturday 25th September 2004.

All Full Voting Members will receive a notice in the post in the week following 14th July. If your membership is due to expire shortly before the AGM, you may care to get your renewal application in fairly soon to ensure that you are able to record your voting intentions.



Message from the MGA Chairman

Oxford MGA Centre Appeal

Many thanks to all of you who have made generous donations in response to our special appeal for funds in support of the Oxford MGA Centre. Your response has been outstanding; it will give a major boost to the efforts we are making to ensure the future of this essential facility. It will also be a great encouragement to the MGA staff and everyone else who plays a part in our fundraising efforts.

Annual General Meeting

You will see a notice elsewhere in the Newsletter about this year's Annual General Meeting. I ask all Full (voting) Members of the Association to pay particular attention to the various papers which you will receive about the AGM this year. As a result of a special resolution passed at the 2003 AGM we are introducing a new system of proxy voting this year. This will allow you to say exactly how you wish your proxy to vote on each motion on the AGM agenda. If you have any questions about the procedures or documents – please contact the MGA Head Office Staff.

New MGA Trustee

I am very pleased to be able to tell you that the MGA Board has appointed Mr. Robert Wright as a Trustee and Director of MGA. Robert was previously a Trustee for a short period and he has agreed to take up the burden again. The Board is extremely pleased that Robert has agreed to serve the MGA again in this way.

Robert is a lawyer, who works for the Crown Prosecution Service. He is also heavily involved in the management and running of his family ancestral home (Eyam Hall, Derbyshire), which is open to the public.

In May 1997 Robert wrote an article for MGA News which described his reactions and experiences on being diagnosed with MG; you can read this on the MGA website at: <http://www.mgauk.org/mganews/ski.htm>

MGA Board Minutes Secretary

The MGA Board needs a volunteer to act

as our minutes secretary. This honorary post involves taking notes at MGA Board meetings, and preparing draft minutes. The Board meets six times each year on Saturdays, near Derby, and also once at the AGM venue.

If you are interested in doing this essential job, or know of someone else who may be interested, please contact me – c/o Keynes House.

PETER FINNEY, *Chairman of the MGA Board.*

An Update from Alasdair Nimmo (CEO)

Hello Everyone,

In addition to meeting our agreed budgets, our major goal this year is to raise our profile and create awareness of Myasthenia Gravis. To achieve this, I am pleased to let you know that our awareness campaign, which is being fought on two fronts, is gathering momentum:-

1. Guinness World Record Attempt

The Simultaneous Low Impact Workout, benefiting MGA and the BBC Children In Need Appeal will take place on 19th November at locations throughout the UK and Ireland. This will hopefully create awareness and also raise funds. Full details can be found at www.mga-charity.org/sliw. To date the Guinness World Record attempt has been successfully launched using bus stop locations throughout the country and our thanks go to Adshel for sponsoring us. So far we have had well over 100 enquiries from fitness clubs asking for details of the event. Some clubs have already confirmed they will take part. One Region already has a commitment that some 1,500 people from their fitness club will take part – fantastic news! So come on everyone let's spread the news, we need to beat 50,000 people participating on the night to break the existing World Record. Hopefully this major event will more than ensure we create the goal of awareness.

2. Lobbying Members of Parliament

To ask why this Association has no direct Government support, thereby creating

awareness; raise the Association's profile and hopefully, open doors to supportive departments.

Our thanks go to Jim Dobbin, MP for Rochdale, who has helped us with this campaign. We are now embarking on lobbying the various parliamentary houses currently with the help of:

- The Scottish Parliament – Margaret Ewing MSP
- The National Assembly of Wales – Dr David Lloyd, Plaid Cymru Assembly Member for South Wales West: Val Lloyd, Plaid Cymru Assembly Member for Swansea East; Kirsty Williams, Assembly Member Liberal and Jonathan Morgan, Assembly Member Conservative
- The House of Commons – Jim Dobbin, MP for Rochdale and The Reverend Martin Smyth, Ulster Unionist Belfast South

Currently we are waiting to hear from a potential parliamentary representative from the Dáil in Ireland.

Our current approach with our friends in parliament, (and hopefully you), is to help us conduct this campaign as outlined in the letter and postcard enclosed with this Newsletter. Please help us to help you by giving both of these events YOUR FULLEST SUPPORT.

Thank you.

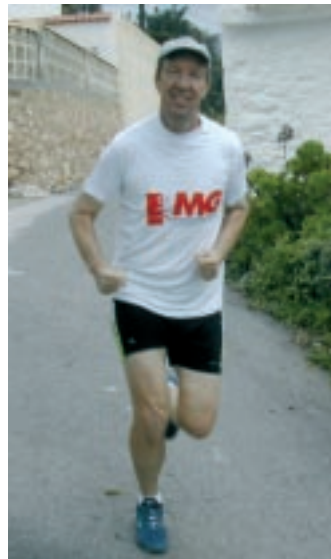
ALASDAIR NIMMO, CEO



Raising funds without spending a penny!

We cannot continue to use landfill sites to dump all of our rubbish so included in this copy of MGA news you will find a recycling envelope for cartridges and mobile phones – MGA's effort to help this situation. All

we ask is that if you cannot use this envelope yourself that you pass it on to somebody who can – and we will receive funds for every item returned. Mobile phones should have the sim card removed, but include the charger – we suggest that you pack this well to prevent damage. POSTAGE IS FREE so this will not cost you a penny. Please help us and by doing so, help save landfill dumping. Remember: Include the battery and re-charger, but remove sim cards – thank you.



It was my first marathon and at the age of 57, despite having trained for some time, I was apprehensive about what was to come and excited at the same time.

The run itself was a moving experience with so many people running for charities, lost loved ones or a cause for which they felt passionately and I was surprised by

the emotion that I felt during the run.

The most depressing part was that having crossed Tower Bridge us slower runners were running alongside the better ones who were on their way back to the Tower and about five miles from home and we were only just passed half way. My split times showed me slowing down on each 10 km sector but the worse was, naturally enough, the last 10 km. Despite the training I was not prepared for the pain and weariness on that last sector, I am ashamed to say that I was reduced to a walk if any incline of one degree or more and the cobblestones of the Tower of London were sheer hell.

Finally, I was running down Birdcage Walk and not far from the finish when a thunderstorm broke leaving everyone feeling pretty miserable but we all made a dash for the finish line and got the coveted medal.

The elation at having finished a marathon was quite a feeling but I swore that I would never do one again as it is more than the human body should have to bear, two days later, however, the anti-climax of no training or preparation turned my thoughts to the possibility of running another marathon, maybe in New York. Time is a great healer.

DAVID N. FRANKS

(Ed. David raised £4,313.21 for MGA at the London Marathon. He did most of his fundraising via our pages at

<http://www.justgiving.com/charity/mga> where he was our Top on-line fundraiser.

Many thanks, David. NB. This site not only raises money for sporting events, but also covers any activity you can think of – memoriam, weddings, anniversaries, etc. Why not visit it?)



The Oxford Medical Conference 17th April 2004 Question and Answer Session

Firstly, three general points:

1. Since each patient is different, we can only give general answers. It would be wrong for us to give individual advice (e.g. on treatment) without knowing all the details (e.g. drug allergies) – which the patient's own Neurologist and GP should have.
2. In autoimmune MG and LEMS, the antibody attack cuts down the reserve capacity in the nerve → muscle triggering. When patients' reserves are low, they are more vulnerable to upsets like infections and certain drugs. On the other hand, if their damaging antibodies have been brought under control (e.g. with steroids), and their reserves have had time to build up again, then they may well withstand the same hazards without trouble.
3. Certain drugs are **suspected** of making MG worse or causing serious side-effects but have never been proved guilty. So, in deciding whether to use them, one always has to balance both the need for them and their known benefits against such potential snags.

Specific Questions:

Q1. Any advice about long-haul air travel?

Answer: We don't expect special problems in MG. The general advice – to drink plenty of water, keep mobile and perhaps wear elastic stockings (to help the blood circulation in the legs) – is especially important for those over 40 and those taking steroids.

Q2. Any advice about what vaccines patients can take?

Answer: Patients who are taking immuno-suppressive drugs (e.g. steroids, azathioprine, and methotrexate) should only take killed vaccines or bacterial products like tetanus toxoid. Live (attenuated) germs can get out of hand in heavily immuno-suppressed people. In patients not taking such drugs, any vaccine should be safe, even after a thymectomy.

Q3. Any ideas about diets and alternative measures?

Answer: Obviously, in general, it is wise to eat a balanced diet and not to get overweight, so as not to overstrain the

muscles. If the MG is well controlled, moderate amounts of alcohol are fine: if not, then the MG can get worse. By their very nature, it is very hard to do controlled trials to prove that any particular alternative therapies, or especially any diets, are good for MG. So we have no hard evidence like we do for orthodox drugs. However, individual patients may well find something that seems to work for them, so there is probably no harm in trying. As far as we know, most available therapies are harmless, though some imported ones are said to contain steroids or heavy metals, so watch out.

Q4. Would taking thyroxine upset my MG?

Answer: No, rather, it should help (as long as you don't take far too much).

Q5. ABOUT MESTINON®:-

5.1. Are there any alternatives to Mestinon® if it is not a success?

Answer: Yes, there is also neostigmine, but it works very similarly, and is shorter-acting, so it is seldom much of an improvement.

Some patients get so much better with immuno-suppressive drugs that they don't need Mestinon® anymore.

5.2 Can cramps and spasms be a side-effect, and are there treatments for them?

Answer: Yes, they can be; if so, try cutting down the dose of Mestinon®. Another general treatment is quinine sulphate, but, if Mestinon® is to blame, that is a bit like swallowing a spider to catch a fly. There are other causes of cramps like over-tensing certain muscles for long periods. A very rare example is a (different) immune attack on the nerve endings – 'neuromyotonia' – which can be calmed down by drugs such as carbamazepine, or even treated by immuno-suppression if need be.

5.3 What can we do about loose bowels/incontinence?

Answer: Looseness can be a sign of bowel over-activity from taking too much Mestinon®. If so, one can cut down such effects on our 'automatic' functions with another drug called propantheline, or prevent the looseness with remedies for travellers' diarrhoea.

5.4 Can Mestinon® affect asthma?

Answer: In theory, it can, but that must be very rare. We advise patients to measure their peak flow before and after starting the drug (ie while blowing out).

Q6. *Can patients with neither anti-MuSK nor anti-AChR antibodies still have generalised MG, and what is their outlook?*

Answer: Yes, they can; if so, diagnosis relies mainly on EMG. The anti-MuSK patients have only recently been recognised as a separate group; several teams now suspect that their MG is harder to control, whereas patients with neither antibody seem to respond better to immuno-suppressants. But we are still feeling our way, so watch this space.

Q7. *If IvIg seems to work well, why not use that permanently?*

Answer: (a) IvIg is only a short-term measure – best used when you need a quick boost.

(b) It doesn't get to the root of the trouble, so taking immuno-suppressants – to bring the immune attack under control – is neater and also simpler.

(c) IvIg is a human product, pooled from thousands of apparently healthy donors. Though it is screened carefully, there is always the risk of some unknown or unsuspected infection lurking there, like hepatitis C, so one can't guarantee absolute safety.

(d) The IvIg itself costs £1,000 each time, let alone the costs of being in hospital.

Q8. ABOUT STEROIDS:-

8.1. *If one goes too far when tapering down to the lowest working steroid dose, and starts to relapse, is it difficult to regain control?*

Answer: No, usually, a modest increase works well and a big jump-up is rarely needed. Such relapses seem less common when the tapering is done very slowly.

8.2. *Would either Mestinon® (pyridostigmine) or steroids upset control of Type 2 diabetes?*

Answer: No for Mestinon®, but, alas, yes for steroids. So patients may well need to be even more careful with their diet and take higher doses of their 'anti-diabetic' tablets than they otherwise would; some even need insulin injections to control their blood sugar. So that might be a good reason for using one of the 'second-line' immuno-suppressants like azathioprine, to help cut the steroid doses right down.

8.3. *Are there alternatives to steroids?*

Answer: Yes, there are several other immuno-suppressants like azathioprine, methotrexate, cyclosporin A and

mycophenolate mofetil. Azathioprine takes many months to kick-in, but it quite clearly helps patients to 'cruise' on lower doses of steroids, with fewer side-effects.

The others are less well tried-and-tested in MG, and are more powerfully immuno-suppressive. So they act sooner, but probably carry greater risks of infections. They all have their own side-effects, and can affect fertility, and developing babies if taken by pregnant mums, whereas steroids and Azathioprine are generally accepted in the UK for use in pregnancy.

8.4. *Can steroids make MG worse?*

Answer: Only in the short-term and at high doses; otherwise, that is very rare – more likely that their side-effects are to blame.

Question 9. Do the SIDE-EFFECTS OF AZATHIOPRINE include:-

a) *skin tumours* – Yes, patients on Azathioprine probably do get more benign ones (e.g. rodent ulcers, as well as warts), but they can easily be treated by local removal.

b) *lymphatic tumours (lymphomas)* – that is highly debatable; at worst, they are rare.

c) *prostate cancer* – No, there is no evidence of that at all.

d) *neuropathy* – No, there is no evidence of that at all either.

e) *causing anaemia* – Yes. Normally, regular blood tests are done to check for side-effects on the liver as well as the red and white blood-forming cells in the bone marrow.

One patient had done very well on steroids for years, but Azathioprine was added-in to help cut down their dose. Alas, that made him badly anaemic (blood count three times lower than normal). But, after he got back on the rails, he seemed to have fewer relapses than before!

He asks '*Could the anaemia have 're-booted' my immune system?*'

Answer: We can't think of an obvious mechanism; however, both the immune system and the bone marrow are so complicated that there might well be ripples that we aren't aware of. Usually, the likeliest explanation is the most boring one – i.e. that it's just coincidence.

It's certainly a classic example of the best plans coming to grief.



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 and we will forward them on.

Dear Editor,

I am wondering if any of my fellow myasthenics or MG medical people have had experience with the need to take (1) Antibiotics for chest infections or (2) Blood Pressure tablets

I do know that penicillins are not compatible – also the cyclines and mycins and associated groups have been found to be unsuitable.

By experience I have found Beta blockers cause instant relapse. I would be very grateful for any help, experience or suggestions to put to my GP to attempt to solve the problem without having to test out countless drugs and then relapse continually. I have had MG for 14 years - my present regular medication is 3 x 50 mg Azathioprine and 1 x 5mg Prednisolone per day - however at the present time I have relapses due to hay fever from the very early flowering Oilseed Rape.

Yours truly,

CHRISTINE MEYNELL-JONES

Herefordshire

(Ed. It is not really right to say that penicillins are incompatible with MG treatments – though that may be correct for some 'mycins' and 'cyclins', and especially for beta blockers. Do remember also that reactions to drugs vary hugely from one patient to another).

Dear MGA Newsletter,

I was diagnosed with MG in December 1998 having suffered for some months with tiredness, drooping eyelids etc. and not knowing what was the cause. One afternoon when driving home both eyes closed simultaneously so I sought advice immediately. I then received a very quick

diagnosis followed by treatment at Ninewells Hospital and Teaching School as I encountered more problems with speech loss and breathing difficulties. I was at that time a full-time Road Safety Officer and Crash Investigator with Tayside Police having retired from the Force early in 1996 after more than 31 years service. Two years ago I was forced to retire again through the effects of MG along with Sleep Apnoea and so sympathise with the sentiments of Lyn Edwards in the Spring 2004 Newsletter. However, being the recipient of occupational pensions can also it seems make applications for benefits such as DLA and Blue Badges somewhat problematic as they will be "checked out" not only from a medical but also from a financial viewpoint. Apart from receiving my Pension Credits, any other applications I have made to date have been rejected. I am simply saying that one should not "expect" to receive such benefits "automatically" just because one has MG.

I was also interested in the letter from Kizzy Hardy in the Winter 2003 edition. About a year ago, I saw a Consultant Endocrinologist, again at Ninewells Hospital, as my weight seemed to be spiralling upwards almost out of control due at least in part to the effects of Prednisolone, Azathioprine, and of course I also take Pyridostigmine. It was suggested I subject myself to a "D1300" diet that restricts daily intake of calories to 1300 and is based on 3 meals per day balanced with strict weights and/or volumes for most meat, fish, cereals etc. but with NO butter, margarine, fat, cheese, cream, extra sugar and the like, and, NO ALCOHOL, and that didn't bother me as I am strictly "TT" anyway. I can honestly say I determinedly stuck to this diet and have been able to reduce my weight from about 19st 4lbs to around 13st 12lbs, a loss of around 5½ stones! To say I feel somewhat better may

be an understatement, but not carrying such extra weight helps to make life much easier – as is walking up hills, stairs etc. as well as giving one the impetus to continue swimming. There can be light at the end of every tunnel and it is probably just a matter of finding the correct lines along which to travel! In connection with this, how many people have noticed that “Scotland’s Other National Drink!”, “Barr’s Irn-Bru” now lists “quinine” as one of its flavourings – food for thought there I think!

Can I conclude with a comment following the information in the recent “Oxford Clinic Appeal” letter of 7th April – “Clinical trials showing that combined treatment with Azathioprine enables patients to use lower doses of steroids”. This HAS NOT worked for me and so after almost 5 years of taking the combination I am to move to other medication to see if that fares any better and so I hope that the results are passed on to our medical supporters who are researching those “who may need different treatments”.

ALISTAIR W. JOSS
Dundee

Dear Sir,

You published my letter last year when I said how difficult I was finding it to work full time in my job as a school bursar and I subsequently wrote to thank those people who had offered me encouragement by way of email, which you also published.

I thought I would let you know that my early retirement on grounds of ill health was subsequently approved on 22nd February, but not without an enormous amount of effort on my part. I was examined by the physician nominated by the Occupational Health Scheme operated by my employer (insurance company) on 29th September and he supported my application. However, this was not good enough for the insurers, who then sought a second report from my consultant. He stated that it was unlikely that I could return to my job and I independently sought an opinion from another consultant neurologist on a private basis, who also supported my case. This constitutes two specialist opinions and one general medical opinion in anyone’s language, but this was not good enough for

the occupational physician, who again refused my application on the grounds that the long term prognosis was not clear and he expected the condition to remit at some stage, making the issue of eligibility for health retirement questionable. As I had been suffering from the condition since 1997 and was taking 100mg of steroids and Azathioprine at that point, I began to wonder how much the occupational physician knew about MG and, more to the point, how much he was willing to find out – very little on both counts, in my opinion.

I was particularly angry to note that the occupational physician regarded my fatigue as a “subjective” symptom, despite never having examined me.

I spent almost 5 months living with the possibility of losing my home, which did my condition absolutely no good at all. The next stage was for my case to be referred to the Pensions doctors. Coincidentally, when I told my Personnel representative that, if the Pensions doctor turned down my application, I was prepared to take it all the way to the Pensions Ombudsman, I was granted my ill health retirement overnight.

Having been retired now for two months, I am now working on reducing my dosage of drugs and it helps enormously to be able to rest when needed. In addition, I do not suffer breathing difficulties as frequently as I used to, which caused me enormous anxiety. I dare say mine was not an isolated case, and if anyone is finding MG impossible to manage whilst working full time, it is worth pursuing ill health retirement and not giving into the opposition employed by insurance companies. By the way, my partner and I attended the conference at the John Radcliffe last weekend and thought it was very worth while to attend.

Your sincerely,
JULIE LEE

Dear Sir,

I was interested to read in your Spring Edition that a clinical study on Mycophenolate Mofetil will be starting soon in the UK. I have been on this drug since January 2002 (2,000 mg daily) and I am also on steroids (prednisolone), which are now reducing. I take 240mg of pyridostigmine daily. I also attend



the Royal Free Hampstead every 3 months for infusions of immunoglobulin and I have now received ten treatments (18 bottles each time) commencing in October 2001. Although my MG symptoms are a lot better, I am suffering from terrible nasal congestion, and I have been unable to taste or smell for most of the last 12 months. I should like to know if anyone else on these treatments has suffered from similar side effects, and I shall be waiting the result of the clinical study when they are published.

Your sincerely,

DAVID CLEEVER

(Ed. We have no further feedback at this time regarding the Clinical Study. We will, of course, publish any information we are given in due course)

Dear MGA,

Thank you for the latest Spring MGA Newsletter. Always informative and I do like the 'Feedback' section in particular. It seems clear there are many people suffering from MG badly but as my experience has been less serious, I thought you may like to hear my own presentation of the disease. I am now 58 years old.

Four years ago, racing down the M1 in the fast lane from Northampton to Milton Keynes for an urgent meeting, my left eye suddenly shut. And it shut completely. Despite a few frantic tugs, at around the legal limit, it would not open. Ever so gently and feeling pretty unbalanced, I pulled over on the hard shoulder wondering what had happened. I felt generally well but somewhat weak and tired. Who doesn't living an active life in a busy world?

Being a stout minded fellow, I drove on to MK, albeit a little more steadily, to my meeting at which I spent head on arm trying to conceal my annoyingly in-operative eye lid. More embarrassment rather than fear of ill health, I have to admit.

After the meeting, a quick call on the mobile and it was a gentle one-eyed drive back up the M1 and to my GP where I was diagnosed by a temporary junior doctor as having had a mini-stroke. I had to admit for the previous few months of being tired, trouble chewing tough meat, and of all things, difficulty in spitting out my toothpaste! Why had I not responded to these peculiar

symptoms before?

So now, instead of springing up and down the motorway, my driving licence was withdrawn and I was travelling by taxi, train, bus, wife and feet thinking that at any moment now another stroke will hit me. This does level the mind, especially being driven by the wife!

After seeing my regular GP, I was referred to a great lady neurologist at the Walsgrave Hospital in Coventry who prescribed several months of outpatient tests of all sorts, including scans on my entire being (excepting my willie and my feet).

After a week's further tests in hospital, including a very nice white-haired gentleman giving me electric shock torture treatment (supposedly to record the speed of neurological signals to muscles), my neurologist suspected that I had not had a stroke but perhaps something called Myasthenia Gravis.

The romance of having a very rare disease left me quickly.

A double-blind test was carried out where the last part was an injection of Mestinon. Wow! Not only did my eye lid open almost immediately but my upper body strength returned with real vigour. After this I was prescribed high doses of drugs which have over the years reduced to very little at 5mg of Pyridostigmine on alternate days only and ranitidine to protect my tummy.

I still have MG but my medication is small and whilst remaining very watchful for the symptoms I previously ignored, I am pretty healthy. I see my neurologist every 6 months and I am always coaxing her to reduce my medication yet further. Can MG disappear and could I finish the drugs completely at some point? I wonder.

Little seems to be known about MG and whilst I have read and continue to read all available information, I would like to see more research and published information on how to manage the disease for those severely affected, and folk like me who are lucky enough to have a mild form of the disease.

Your sincerely,

PETER J. WADE
Dunchurch



I missed the deadline for the last edition of MGA News, the reason? Mrs Gravis and I were suffering from the father and mother of a head cold, come chesty cough, come, well you name it. I believe that

the medical term is 'there is a lot of it about'.

We treated ourselves using our favourite family home remedies, all of them over the counter products obtained from our local pharmacy. The valuable thing about our local pharmacists, a husband and wife, is that they both know all about me. They are aware of my condition and of all the medication I am on and guide me as to which of the over the counter medicines I can have without them effecting either my MG, or interacting with the prescription drugs. For instance they steer me away from one well known analgesic product because this has quinine sulphate as part of its make up and quinine can cause an increase in myasthenic weakness. Sadly this warning also applies to a 'G and T', Indian Tonic Water also containing quinine. When in doubt about anything, they refer to their computer database which has a record of all the medicines I take, and can cross reference these with other preparations.

If you live with MG then the real secret is to know when to call on your GP for help. After four weeks, much inhaling and the occasional firm exchange with Mrs Gravis on the subject of who was suffering most, we had both managed to throw off the infection. I, however, was left with a sinus problem which was also beginning to stimulate my MG, so it was off to see the Doctor, who prescribed a short course of antibiotics. He too has a wonderful computer with a cross referenced database, which promptly told him in bold red letters, with bells and whistles sounding, that every antibiotic he wished to prescribe was not recommended for Myasthenics. Fortunately we had encountered this before; advice from the consultant was that where the MG is under control, the use of suitable antibiotics, carefully monitored, would be safe. There has to be a balance between the possible

side effects from the antibiotics and the potential myasthenic problems which can arise if an infection is left untreated. Each patient is different, Mrs Gravis says in my case peculiar, so that the treatment has to be tailored to each individual. I believe that both GP and Consultant should be involved in this process.

To get my head really straight, I thought that I would see what an 'Indian Massage' could do for me. We have a practitioner in our village and so I gave her a bell and an appointment was made. Mrs Gravis is used to my trying complementary therapies and given the fact that both she and Christine, the 'Head Massager', are members of our local Gardening Club, there were no objections from management. The session took place in our front room, me sitting on a foot stool and Christine working from behind. As she gently worked on my head and shoulders I could feel the tension fading away and I became much more relaxed; I am told that some patients actually nod off. When the treatment was ended I was told to drink a glass of water and to then make sure that I drank several more during the rest of the day. The idea was to flush away any toxins that I had released as a result of the massage. This seems to be a common factor with many therapies, Shiatsu, Aromatherapy and Chiropractics amongst others. My experience has been that it is wise to follow this advice, drink the water and lay off the coffee and tea. When I have failed to do so, I have experienced a sensation like a mild hangover. Not a truly scientific assessment I know, just one Gravis being treated, but it did seem to do me some good and I am going to have another session. Of course, these therapies cannot cure MG, but I find that they can alleviate some of the symptoms. As with all health issues, I have discussed complementary therapies with my GP, his feeling has always been that if it does no harm it may do good, and he will always warn me off anything suspect. I always use therapists who belong to the appropriate controlling institute or association. The other thing that has given me confidence is that all of the practitioners I have used have been keen to write to my GP and tell him what they are doing.

Gravis.





The East Devon and Exeter Branch of MGA were the recipients of £400 raised at a fashion show at Exmouth Rugby Club, organised by Exeter Ladies Circle. Around 90 ladies enjoyed the show and snapped up the bargains afterwards.



Picture shows Ian Cooper who raised a fantastic £14,750 by running in the London Marathon being congratulated by Jane Whittingham, Trustee and Chair of the Gloucester Branch of MGA, surrounded by local branch members.

Northants Branch have received a donation from the Corus Tubes in Corby for medical videos to be distributed to GPs in the Northants Region. A big thank you from Pam Stubbs, Branch Treasurer

Angel Flights have information on free transport in private aircraft for people who are ill and unable to travel in public transport. They can be contacted on 020 8778 6427

Enable Holidays

Are offering a brochure featuring a range of package holidays for disabled people, their families and friends. They claim to have the best and most comprehensive information that you will need to make the best possible choice. You can contact them on 0871 222 4939 or via www.enableholidays.com

"Leap on the Moor" was a very successful event in conjunction with the Dartmoor Railway, and raised £1,000. The Mayor of Okehampton, Mrs Christine Marsh (4th from right) and Robin Townsend (far left) manager of Dartmoor Railway are shown along with local members of MGA.





Gavin is two thirds of the way through his challenge of a beard for a year for MGA. When it comes off on September 7th, he'll have the ultimate tan line!

Things have been growing very well! Over £1000 has been raised so far and the website charting his progress has received lots of visitors, over 8000 in three months. It is spreading the word of MGA across the net with visitors in USA, Africa and the Far East. Please have a look at his site and pass it on to all your friends because more visitors will help secure sponsorship of the site

(adding to his fundraising total). If any one knows of potential 'hair and beauty' sponsors please get in touch with Gavin on info@beardforcharity.org.uk or 023 80363344.

The website is www.beardforcharity.org.uk It is constantly updated with pictures, trivia and comments so go and have a laugh. If you thought a 25 year old couldn't grow much of a beard then think again . . .

If you would like to vote in the biggest award ceremony of 2004, the Beard Oscars. "Whose is the sexiest beard, what's the best beard in a movie and who has the best beard". Vote now! At the web page below . . . many thanks.

<http://pub43.bravenet.com/vote/vote.php?usernum=3649571613>

The MGA Young People's Club

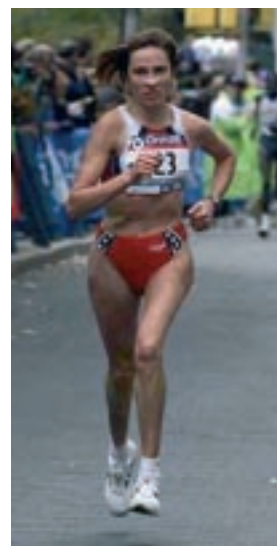
As an RO working in the Southwest and South Wales, Rita Goldthorp has been surprised at the number of children and young people who have MG. Following a recent meeting with Clare, an 18 year old who has had MG since about the age of 10, Rita is thinking about setting up a special group for these young people. In the next few months she will be sending out press releases to newspapers, local radio and TV

asking for young myasthenics to contact her. Clare, will, on behalf of MGA, be running this new club to enable young people to contact one another on a pen pal basis. The options will be letter, telephone and email and all correspondence with Clare will be via The Myasthenia Gravis Association, PO Box 5859, Sherborne DT9 4ZR. So if you are aged 7-11 (range 1), 12-18 (range 2) or 19-25 (range 3) then why not drop Clare a line and then take it from there.

The Flora Light Challenge For Women

Be there – Be a part of it with MGA

On Sunday 5th September 2004 the Flora Light Women's Challenge will take part simultaneously in London's Hyde Park and in Birmingham City centre. Whatever your age, fitness levels or running ability signing up to take part in the Flora Light Challenge for Women is a great incentive to keep fit and feel healthier. This is a 5km run – or walk – for women of all ages and abilities whether fit or not quite so fit! To book your place, please send a cheque for £20 (entry fee plus donation to MGA) together with the completed form below. MGA will make one application for all entrants. Sponsor forms will be supplied by MGA.



I would like to apply for London or Birmingham

First Name..... Last Name.....

Address.....

Post code.....Tel No.E.mail

Date of birth Signed..... Date.....



IAN COOPER

The Unlikely Marathon Runner

- Dec 2002 passed significant age of 60, Company medicals demanded.
- Passed fit despite being chronically obese.
- Jan 2003 time to start new lifestyle.
- Joined gym and paid slightly more attention to diet.

As pools of sweat formed on gym floor, I was encouraged to resume my running career from which I had retired 43 years previously. Gentle progress made from running 10k races to various Half Marathons. However, the ultimate challenge lay ahead. Late one night I was dared by various couch-potato colleagues and friends to enter the London Marathon. After careful consideration and another bottle of wine my resolve weakened and I agreed to apply for a Marathon place provided the same colleagues and friends helped with sponsorship.

I had no difficulty in choosing a Charity as I was diagnosed with Myasthenia Gravis in 1972. I had a Thymectomy in 1977 and thanks to the care of Professor Newsom-Davies and his colleagues, my health gradually recovered. Although I had a slight relapse in 1984. Again, with the help of the MG team in Oxford, I have been symptom free for 19 years. I am acutely aware that I am fortunate to be one of a minority who appear to have made a complete recovery from MG.

The Day of the Marathon

One of the best days of my life. The weather was atrocious but I hardly noticed. I knew that my 15 months training programme of running up to 35 to 40 miles per week had prepared me for the physical endurance but what I had underestimated was the excitement and the



comradeship of fellow runners each of whom had their own special story to tell.

- The elderly blind gentleman being guided round the 26 miles by a young lady volunteer.
- The man running for Leukaemia Research with a picture of a

Not the easiest first full marathon for former Regional Organiser for London South, Phil Rossall. The heat and the hills at the Halstead Marathon (Essex) on Sunday 16th May made it hard work



(and a slow time!), but Phil managed to complete the 26.2 miles and raise over £210 for the London South-East Branch. Phil passes on his thanks to the generosity of members of all the South London Branches.

young girl on his running vest with the words 'In Loving Memory of My Beautiful Daughter'.

- A 77 year old man running his 77th Marathon, 17 in London with the remainder around the world.
- The young girl supporting Cancer Research, at the finish in tears as she told me about her Mum who had died the previous year from Breast Cancer.

The crowds were fantastic. On my MG shirt I also had my name. For the last few weary miles along the Embankment the crowd seemed to be especially supporting me as they shouted my name in encouragement. Being 4.5 stone lighter than I was 15 months earlier helped me to a finishing time of 4 hours 22 mins. which seems fair for a first time 61 year old marathon runner.

With the help of my friends from Chateau Bauduc near Bordeaux I was able to run a number of sponsorship campaigns, each of which offered a case of wine to the sponsor who most accurately forecast my finishing time. This, of course, encouraged sponsors to send funds before the day of the Marathon.

As a result I have been able to send almost £15,000 to the MGA as well as over £1,000 to the Children's Chronic Arthritic Society, a charity supported by colleagues at work. I promised my wife that the London Marathon was a one off event but having been married to me for 36 years she knows that I occasionally tell lies.

Perhaps she would be interested in a shopping trip to New York provided it coincided with the NY Marathon?



South Manchester Branch (below) received £500 from British Homing World Show of the year – thanks to **Jack and Mary Handley**. The branch have also been adopted by

Great Moor Conservative Club in Stockport as charity of the year and a sponsored walk is planned for August Bank Holiday. **Dr Ian Hart**, senior neurologist at the Walton Centre was guest speaker at **Merseyside's May Branch AGM** meeting. Chair, **John Evans** was re-elected as Chair and a presentation was made as a thank you – our thanks go to John and Eileen his wife for outstanding support.



Wigan Branch received a donation of £100 from Hindley Rotary Club and **Ian Atkinson** raised £479 with an abseil. **York Branch** are to benefit, thanks to **Margaret King**, from fundraising activities at Pocklington School and a charity dinner is also planned for September in Stamford Bridge. **Leeds Branch** are also to have a charity dinner on June 18th at Rawdon Golf Club.



West Yorkshire Branches were supported by **Publico's Drinkers Delights Pubs** with their first

events. Bungee jumps over Easter raised £3,311 in Bradford, and Firewalks are to follow in Leeds. Bungees and Firewalks are planned during the year throughout West Yorkshire – for details tel Steve 01457 766410. **Picture shows Steve Annable with Paul Crompton – Operations Manager for Publico with Bradford Bulls Mascot** who popped along on the day with Huddersfield & Brighouse Branch members to give support.

Brighouse Branch had support from local Belly Dancers raising £170 thanks to **Sandra Simmons**. Thanks also go to **Harry Smithson and Val Broom** for their continued support. **North Manchester Branch** are holding a Charity Ball at Bolton Wanderers Reebok Stadium on 20th November. Tickets priced at £30 include superb food, entertainment and charity auction. Auctioneer for the evening will be ex-professional footballer **Iain Dowie** who is now manager of Crystal Palace following a very successful time as manager of Oldham Athletic.

Lancs Branch raised £175 thanks to a supermarket connection in Preston. **Roy and June Robinson of the Birley Arms** in Preston raised £311 for the branch plus £88 from Fulwood Leisure Centre for a Christmas Raffle - thanks to **Terry and Joan Jump**. **Warrington Branch** will be at Walton Hall Gardens in July for Warrington Awareness Day – look out for their stall and support them. **South Yorkshire Branch's** summer events include **Sue and Chris Hudson's** Strawberry Cream Tea in Retford on July 17th- are not to be missed with book, plant sales and home made stalls. Thanks go out again to **Barry Gregory** for sponsoring the branches web site - why not take a look www.mgsouthyorks.org.- the branch also has a new Secretary, **Maureen Cash** who takes over from **Ken Poole**. Ken will still be involved as a committee member and thanks go to Ken for his hard work over the years for the Association and the branch.

Picture shows South Yorkshire Branch receiving a regional award for support in the community



and were very pleased to receive a further National Award as Community Champions. They also received a grant from South Yorkshire Key Fund to help host their Regional Conference last year which attracted over 100 visitors – WELL DONE!



Region 12 — KAREN RYNNE — Tel: 00353 65683 4444

E-mail: karen.rynnne@mga-charity.org



This photo was taken for the Co. Wexford Newspaper in the South East Radio Studio following a live radio interview discussing MG.

Edel Sheridan has MG and together with her husband Pat raised €1600 for MGA from councillors in their area. The cheque was presented to Karen on October 14th 2003.



Web Sites of Interest:

Lincs Branch notified us of an interesting site which they say is very good especially for newly diagnosed people as it talks you through the illness. You can find it here: <http://www.nlm.nih.gov/medlineplus/tutorial.html>

You may be interested to know that since we have been putting our MGA Newsletter on the World Wide Web (the Internet) we have had over 5,000 downloaded editions covering 2001 to date. This is from people scattered across the whole World.

Gerrard saves MGA £51,000

Following on with his bus stop campaign, Gerrard McMahon has managed to place further posters in 395 panels in some of Britain's top Health and Fitness clubs. Not only that, but he has been told that they will keep the posters for when the frames are not being used commercially and then re-use them again.

The rate card for this many panels would be over £51,000 for two weeks and in many cases our posters will be on display much longer than that.

Additionally, there are new frames being installed in June giving a total of 450 panels nationally. This means we will be impacting over 2.8 million adults who work out regularly in Britain's top health and fitness clubs.

NEW YEAR DRAW—PRIZE WINNERS

1st prize of £1,000

Mr. F. H. Harper, Harrow, Middlesex

2nd prize of £250

Ms. S. King, Carlaway, Isle of Lewis

3rd prize of £100

Mrs. G. Stewart, Wisborough Green, West Sussex

Runner up prizes went to Mrs. V. Still of Orsett, Essex and D. Mauger of London.

Wiltshire Farm Foods supply frozen meals directly to people's homes. There is a choice of 175 meals and desserts with prices starting at £1.60. These meals are ideal for people living on their own, or for when MG takes its revenge and lays people too low to be able to cook. If you are interested they can be contacted on 0800 773 773 or via their website at www.wiltshirefarmfoods.com



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
Autumn 2004	6th August
Winter 2004	12th November
Spring 2005	11th February
Summer 2005	13th May



Myasthenics in **North Devon** had the opportunity recently to meet with two Occupational Therapists from the hospital in Barnstaple. Nicky and Jo came along to a meeting to talk about their work, show items of equipment that can benefit Myasthenics, but more importantly to learn more about the illness from those who have it and live in their locality.

Nicky started by explaining the role of an OT, which is to 'maintain people's independence in a variety of ways. Adapting people's environment and giving advice on small adaptations to help daily life. Energy conservation is very high on the list for advice.'

If you have never been assessed by an Occupational Therapist it was suggested that when you next visit your neurologist that you should ask for a referral. Alternatively, you can ask your GP to refer you to a local Social Services OT who can help you with advice on shower and bath adaptations, grab rails, dealing with steps and stairs and obtaining blue badges. Another therapist who you may find very helpful would be the Speech and Language Therapist who will help with swallowing, if food is a problem for you. Contact is via your GP.

Nicky and Jo then proceeded to show a selection of equipment that would be helpful on a day to day basis for conservation of energy. Catalogues were distributed for Keep Able 08705 202122 and Chester Care 01623 722 337 but with the emphasis of 'do contact your local social services for advice on the best equipment to solve your problem' before purchasing anything.

The East Devon and Exeter Branch at their recent meeting held a discussion on the provision of blue badges. The majority of members present felt that they would benefit greatly from having a badge to enable them to park nearer to the supermarket door, nearer to the shops etc. The members are now organising their own campaign for badges which they hope will link well with the Children in Need lobbying. Each member plans to ask their neurologist to refer them for a badge – this will probably have to be via the Occupational Therapy Department (see above).

They will then follow this up with letters to their MP if their applications are unsuccessful. We will report further on this campaign later in the year.

The Southwest Regional Meeting was held at the MS Centre in Exeter on May 8th bringing around 32 Myasthenics in the area together for the day. We had excellent speakers and demonstrations from Possum Controls, Alasdair Nimmo and Peter Finney. Members felt that they had learned a great deal and they look forward to our next meeting. An excellent buffet lunch with wonderful home made cakes was provided by Lyn, Judy and Clive from the South Devon branch. (Pic below).



Laugh! I nearly cried . . . **Newspaper headlines**

"Police have begun a campaign to run down jaywalkers." "If the strike isn't settled quickly, it may last a while." "Red tape holds up new bridges."

Any more out there?

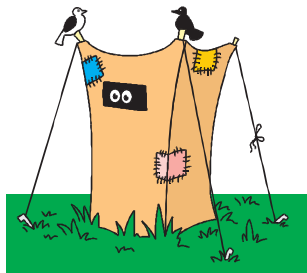
Poetry

If you like poetry and can access the Internet, then try these from one of our members. Go to www.poetry.com and do a "Poet Search" for "Goldman" "Jonathan"

The poems you need are: "Onwards from Depression" - "Myasthenia Gravis" - and "Muscle Spasms"

There are many others there as well. Thanks Jonathan.





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@mgaug.org.uk

Helplines:

UK 0800 919922

Ireland 1800 409672

Websites:

www.mgaug.org

www.mga-charity.org

Registered Charity No: 1046443

We're on the WEB

www.mgaug.org

and

www.mga-charity.org

The Association does its
best to ensure that the
information contained in
this newsletter and on its
website is as complete and
up-to-date as possible at
the time of publication,
but cannot accept any
legal or other liability

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200 CLUB WINNERS

Draw February 2004

1st: MRS. P. PHILLIPS, Harlow, Essex – £60
2nd: MRS. E. COTTRELL, Satal, Bebington – £30
3rd: MRS. D. HINDLEY, Bolton, Lancs. – £15

Draw March 2004

1st: MRS. K. GARVEY, Bury, Lancs. – £60
2nd: MR. E. A. BENN, Cumbria – £30
3rd: MRS. M. WINNING, Whitefield, Manchester – £15

Draw April 2004

1st: MR. D. ESSON, JNR, Buckie, Aberdeenshire – £60
2nd: MISS Y. HURLEY, Bromley, Kent – £30
3rd: MRS. M. LEONARD, Dundee – £15

A FEW SPACES STILL AVAILABLE FOR MEMBERSHIP OF THE 200 CLUB

(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 to MGA) *Please*
2. Full remittance of £12 enclosed *tick one*
3. Bankers Order (please complete below) *box only*

BANKERS ORDER

The Manager (full bank address please)

Please send in today and
enclose SAE - Thank you

Sort Code _____ Account No. _____

Account Name _____

Please pay to Myasthenia Gravis Association, Account No. 61214950,
Sort Code 40-33-30, HSBC, 15 Uttoxeter Road, Mickleover, Derby DE3 5DA,
the sum of £1 per month for 12 months commencing on 1st August 2004.