

YORK BRANCH WINS

JOHN NEWSOM—DAVIS AWARD

At the Yorkshire Regional Conference held on 29th September, members of the York branch were delighted to be presented with the John Newsom—Davis Trophy for their outstanding contributions to MGA through fundraising and awareness raising in 2013.

They are pictured below with MGA CEO Ruth Ingledew, MGA Regional Organiser, Linda McDonald and Leeds United Footballing legend, Norman Hunter, whose daughter, Claire, has MG. Congratulations to the branch members on winning the award for a second time.





An Update from Ruth Ingledew - MGA CEO

The online auction was a huge success – with lots of bidding on the many donated items raising over £800! We were so pleased with the result that we plan another auction early next month and will probably repeat the event again next year. Please get in touch if you have any more items to donate and keep bidding on those bargains to support our work!

We are still working on the feedback from the members' survey – many of you had a lot to say about our logo and style. Work is underway on some changes for next year, watch this space!

We continue to work with Neurological Alliance nationally to lobby for improved health services, particularly in the area of specialist commissioning for neurology. Thank you to those members who are getting involved in their local NHS patient groups. At a time of such big changes in delivery of health services it is important to make sure that our voice is heard nationally and locally. If anyone would like more information or advice on how to get involved in their own areas to make sure that the health needs of people with myasthenia are promoted, please get in touch.

October was a busy month for those of us based at Derby. We were fortunate to secure alternative offices which give us more useful space and save the charity some money. We are still at the College Business Centre and so our address is the same as before, no need to change your address book! We were most grateful for a number of very generous donations of office furniture and to receive funding for a much needed photocopier. Thanks to a mammoth effort by everyone the move went very smoothly and we are now settled in to the new space – if anyone is visiting Derby please do come to see us.

Many of you know of our Benefits Officer, Steve Bradshaw. In the last year he has given one-to-one advice to over 220 members on subjects as diverse as DLA; Blue Badge; ESA; Attendance Allowance and Access to Work.

He is a mine of information on the new Personal Independence Payments (PIP) and with his personal experience of MG can really help members to access the benefits and service entitlements that can make life easier.

We were so pleased to receive this letter from a member who has used the service recently.....

"Last Thursday I attended a Tribunal to decide whether I would still be allowed to get ESA for Myasthenia Gravis.

The appeal process has gone on for over a year.

During this time Steve Bradshaw has been supportive, well-informed and instructive. He gave me a 'plan of attack' with which to structure my appeal, so I had a format on which to hang all my evidence. He gave me specific words to use within letters to make my point. All in all I couldn't have faced the Tribunal Panel without his words of wisdom.

For all us Myasthenics it's great to know the Association and its experts are there when we have our backs to the wall and there seems to be no escape!"

Thank you.

It is always great to see so many varied events taking place for MGA – without these and the fantastic support of members, families and friends we could not continue our work, thank you. If you have any new ideas to raise funds for the charity, or have any other thoughts or comments about MGA, I would love to hear from you.

Wishing you a Happy Festive season and Prosperous New Year!

Ruth Ingledew – MGA CEO

FOR EACH IS A JOLLY GOOD FELLOW...

As you know, some of the MGA's proudest products are the Trainee Neurologists whose PhD projects we fund. Not only do they usually do some very useful research: they also learn about treating MG patients and go on to become good friends to their local myasthenic communities where they finally settle (as many of you from near Belfast, Glasgow, Manchester, Oxford and Southampton will know). Thanks to a large legacy, the MGA funded two Fellowships about 4 years ago, and named them after our late President, Prof John Newsom-Davis, CBE, FRS. It just so happened that both the highest rated applications were about the LEMS. Here are final reports from the Fellows, who have just finished.

Dr Jennifer Spillane worked with Prof Dmitri Kullmann at The National Hospital, Queen Square / University College, London. Her lab project was about how **LEMS** patients' antibodies cause the weakness. We already knew that they actually recognise calcium channels on the outer surfaces of the nerve endings. When electrical signals arrive from the brain, these channels normally open, and that causes release of the chemical signal 'ACh' which then triggers the muscle. One of the various types of calcium channel is called P/Q. With kind help from the LEMS expert, Dr Bethan Lang (Oxford), and using cultured nerve cells as a natural test-bed, Jennifer now finds that their P/Q channels are indeed the main target of the patients' antibodies. What's more, these antibodies really do reduce the amount of ACh that the cells release from their internal stores. She hopes that, eventually, her work might help others to develop even better drugs than DAP to soup up ACh release in the patients. On top of all that, Jennifer also did several clinical studies, mainly on **MG patients**:-

1. on 89 patients who had had **thymectomies*** at Queen Square over the previous 10 years. She found that about a third were in 'complete stable remission' without needing **any** drugs, and another third were being successfully kept in remission by drugs like steroids (whose doses could gradually be cut down). Overall, they seemed to do very well, but, obviously, there were no 'controls' given the sham operations that would be needed for rigorous proof. *As you probably know, the **thymus** is where many of our immune cells are first produced. It seems to be involved in starting off the 'autoimmune' reaction in younger MG patients, and they are the ones who **seem** to benefit from its removal (thymectomy). To prove that formally is one main aim of the ongoing International Thymectomy Trial.

2. on 38 MG patients who had been in **intensive care** over the last 12 years, and on their outcomes afterwards. Interestingly, over half of them were aged over 50, and nearly half were newly diagnosed on arrival in the ICU. Over half needed artificial ventilation; nearly all were given IvIg, and 90% did very well.

3. on 5 patients with **thymomas** that recurred 6 - 15 years after they were originally removed. Importantly, there were no obvious warning signs that these slow-growing tumours had come back – ie no worsening of the MG. Thus – for certain thymoma types – regular scanning is needed to catch any recurrences as early as possible, however mild the MG may seem.

Jennifer is now completing her Neurology training in North London.

Dr Paul Gozzard worked with Dr Paul Maddison in Nottingham and with Dr Bethan Lang in Oxford, again mainly on LEMS patients. As you may recall, about half of them have (smoking-related) 'small cell' lung cancers*. These have similar calcium channels, and seem to immunise the patients against them, causing the LEMS weakness. If they do, the LEMS acts as an early warning sign, leading to earlier diagnosis of these cancers. What's more, their growth seems nearly 2x slower – as Paul's studies now confirm rather convincingly. That seems to be an effect of the immune attack, so having the LEMS isn't all bad.

*The other 50% of LEMS patients are mostly non-smokers, and never get lung cancers. The autoimmune attack is very similar, but its cause is a mystery, as in nearly all MG patients.

When the two Pauls next screened 260 regular small cell lung cancer patients, 9 of them turned out to have the LEMS, and a further 12 had other autoimmune disorders that affected their brains instead. What's more, about half of these disorders had not yet been suspected by the doctors treating their cancers – perhaps because they had only rather subtle effects.

Using a variety of methods, Paul next confirmed that the LEMS antibodies really do recognise the calcium channels themselves and not some near neighbours on the nerve cell surface (as can happen with other targets). He also found extra antibodies against some other signalling proteins inside the cells – in about two thirds of small cell lung cancer patients with the LEMS, in one third of those without it, and in hardly any LEMS patients with no tumours.

On top of all that, Paul produced an 'audit' of the 180 patients he saw in Muscle Clinics, including 79 new ones and 102 for follow-up. Fifty had MG, and others had various other muscle disorders, so he gained a lot of valuable experience in their management. That should stand him in good stead as he completes his training in Sheffield and afterwards.

We wish both Jennifer and Paul every success in their careers. ... and so say all of us.

Nick Willcox, Winter 2013

PS You may have heard that Prof Fred Sanger died on 20th November 2013. He's the great hero whose work laid the foundations for the human genome project, as I described last time ("The impossible takes a little longer"). He got two Nobel prizes before he retired 30 years ago: a truly great innings.

Münster Marathon Germany

On 8th August I received the email below from Hector, a neurophysiologist working in Germany. After checking that it would work in Germany, I suggested that we give him an MGA running vest and he gets sponsored for the marathon, by setting up an online JustGiving page. Hector agreed and we sent him the vest along with some of our information leaflets.

Since then he has held a BBQ to raise awareness of myasthenia and has completed the marathon, and is raising sponsorship. He is planning more short races this year and two marathons next year, and he is of course going to wear his MG vest. We wish him well and thank him for his support.

Dear Linda McDonald,

I have recently been diagnostic with MG, I am on an early stage. I am also a Marathon runner whom I do not want to stop just because of the disease. I am writing you to ask where I can buy a running vest from the association, I would like to wear it on my next running (Münster Marathon, Germany) as a support of the people that are suffering like me. Thank you very much for your attention. I have included a link about my feelings on running and MG.

<http://www.moonjoggers.com/rocking-roads-running-partner-named-disease/>

Hector Romo—Parra

Linda McDonald, Regional Organiser

In this issue of Nurses Corner we have invited Sarah Scott of Hampshire to give us an insight into the relationship she has with Myasthenia Nurse Natalie James.

Me and MG

I was diagnosed with Myasthenia Gravis in August of 2011. I was residing in the Caribbean and recovering from surgery to remove a thymoma. It was only when my breathing became extremely difficult and I could not swallow, plus a host of other symptoms, that the surgeon finally suggested that I might have MG. Up to this time he said my symptoms were normal after major surgery and I just needed physiotherapy. With the physio I got worse and worse to the point that I believed I would die.

The first contact with the National Hospital for Neurology and Neurosurgery in London was through Natalie James who was in turn contacted by the friends who were caring for me. Natalie liaised with them, and her advice on medications and most importantly dosages probably saved my life! It became apparent that I would need to return to the UK so as to seek proper care for my condition. Upon referral from a doctor, Natalie arranged for me to become a patient of Professor Kullmann.

After being so frightened by my weak condition, it was a huge relief to have my fears addressed and explained by the specialist. For the first time I began to think I might get through this.

I had a series of tests to confirm diagnosis. The staff operating the MRI scanner were so kind, helping me overcome my fear of the closeness of the machine. Likewise the "electrical test" which I found quite painful, was bearable because of the caring attitude of the technician administering the test. Overall everyone at the hospital are friendly and caring, which makes a huge difference to how I deal with all this. Above all I think having what feels like my own personal myasthenia nurse whom I can contact at any time is the biggest gift to me. I feel safe and it is wonderful to be able to ask questions and talk to someone who really cares about how I feel as well as being very knowledgeable about my condition. I no longer feel alone. I can't imagine getting better care anywhere else or more caring people looking after me. I am also lucky to have a great GP.

I joined the MGA Hampshire branch, but unfortunately I live a ways from most activities, plus dealing with my illness has kept me from attending a lot of events. I did attend the MGA Conference held at the hospital last year. This was very informative and it was so nice to meet others dealing with the same problems with their illness as I am. I would love to help with fundraising as I think monies for research and to keep the myasthenia nurses is essential. I hope to become more involved in the future.

By Sarah Scott, Hampshire

**Season's Greetings
and a Happy New Year
from all at MGA**





MGA Benefits Service

By Steve Bradshaw, Benefits officer

The ability to work effectively in employment often seems impossible for those with a myasthenia syndrome. Having to take days off sick, coping with fatigue, pressure and stress all compound issues. Yet we are often not aware of the help and support available to keep us in employment. Work not only provides income but also social interaction which makes it important in helping us with self-esteem, routine and countering the feeling of isolation. So if we choose to work, and are in a position to do so, what is available?

There is local support available with practical issues; these are accessed normally via the DEA (Disability Employment Advisor). This support can range from training to CV's and interview support. Contact would be via your Local Job Centre Plus.

Access to Work, which is accessed via the department of Works and Pensions, can with agreement from the employer, carry out an in-work assessment. From this; recommendation on work hours systems and equipment can be made. Access to Work may even fund all or part of any cost for your employer. To qualify the employee normally has to be in receipt of higher rate DLA (Disability Living Allowance), or PiP (Personal Independent Payments). Contact can be made either to the regional office or via the Job Centre. Information is available on the web.

If you receive the higher rate care of DLA or PiP, and work or are employed, then you are entitled to claim the disability element of Working Tax Credits. The hours of work are also reduced to 16 hours a week to enable a claim to be made. Often this extra support goes a long way to compensate for the money lost through reduced hours. Contact is via the Customs and Excise, Family and Working Tax Credits helpline, or on the HMRC web site. This site also contains a good calculator, so you can quickly assess your entitlements.

Steve Bradshaw, Winter 2013

How We Spend Your Money

REGIONAL CONFERENCES

The cost of a regional conference will vary depending on the venue and where in the country the conference is being held.

The average costs for a conference based on a 100 people in the North of England are £4,000. People may think that the cost of hiring a room and providing lunch and tea / coffee are the only costs. The cost of the room hire, lunch and tea / coffee would be in the region of £1,200.

Other costs also include travel and accommodation for guest speakers, hiring of lectern, microphones & PA system, travel assistance for members, publicity and mailing to members and supporters.



Text **OMGM10**
and donation
amount to **70070**

Donate to Myasthenia
Gravis Association and
make a difference today.

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OCULAR MYASTHENIA AWARENESS MONTH

This October was our first ever Ocular Myasthenia Awareness Month, did you join in to help us raise awareness and funds?



Newspaper articles through-out the country were talking about ocular and general myasthenia. Could you approach your local paper next year to get your story told?

Opticians urged to look out for eye disease signs

OCTOBER is ocular myasthenia awareness month and opticians are being urged to encourage their clients with signs of the rare condition to get the right help. Myasthenia is a rare autoimmune disease that can affect anyone of any age. It has no known cure and can be fatal. It affects one in 5,000 people in the UK but many cases remain undiagnosed. Sufferers have fluctuating and debilitating muscle weakness, leading to double or blurred vision, problems keeping eyes open and droopy eyelids. The Island branch of the Myasthenia Gravis Association (MGA) wants to make opticians aware of the condition and to encourage their clients with signs of myasthenia to contact the group. Myasthenia sufferer Lynne Pitcher, of the IW MGA, said: "Very little is still known about myasthenia, not just by the public, but also the medical profession. "We want to change that by ensuring, with the help of opticians, more people hear about the condition. "Early diagnosis of myasthenic syndromes is vital to ensure the best long term care for patients."



Some brave souls even took to the skies and zipped their way to raising awareness for Ocular Myasthenia Awareness Month. Keep your eye out for venues and dates for next year's OMG events

Lots of branches and volunteers held Tea Parties, using our fabulous cupcake toppers. This is just one example. Why don't you order your fundraising pack for 2014

Ocular Myasthenia Awareness Month will become an annual fixture for MGA, so why don't you have a think about how you can get involved next October? Keep an eye out in upcoming MGA News for more ideas and for fundraising packs launching and make sure you're involved next year!



For more details contact your local RO or Maria Martin on 07779 121 621 email: maria.martin@mga-charity.org

'IT ALL BEGAN IN BRIDLINGTON'.....

..... But could have been anywhere at all. May 2012, having breakfast in our caravan my Wife Sylvia commented that my left eyelid was closed, maybe I'm still half asleep being my not unexpected reply. Little did I know that this was to be somewhat of a life changing event until after a one-eyed 150 mile caravan towing journey back to the West Midlands, I visited my GP. Thankfully without much ado, she sent me to the Birmingham & Midland Eye Centre where after many tests & examinations, Ocular Myasthenia was suspected and confirmed after blood tests within weeks. I was then referred to my now neurology consultant who arranged a thymus scan (negative). The situation and its potential was explained and I was introduced to 'Mestinon' it was suggested that the best place to start my internet research was indeed the MGA (he was right of course).

For more than twelve months I adapted to living with the 'nuisance' of my eyelids seemingly having a mind of their own and behaving like tensionless roller blinds. I continued to live life as normally as possible while not thinking much of the potential of things to escalate in the way they did during this late summer of 2013.

Two further holidays on a narrow boat and visiting friends in the USA found me aware that all was not quite right when my neck did not want to support my head, uncomfortable but I coped and we made it home. I decided I could survive the three weeks to my next appointment but My.... asthenia had other ideas.

Having joined MGA, we managed to attend the Birmingham Regional Conference which was of considerable interest and despite my deteriorating condition, very enjoyable and supportive for us both.

By the time I arrived at my consultants appointment I had lost use of all muscles above the elbows, neck, face, jaw, eyes and throat and had limited ability to speak or lift my arms and there was concern for my breathing (FVC). I was immediately hospitalised via Sandwell (West Bromwich) to the Queen Elizabeth Hospital in Birmingham where space precludes me from describing the excellent treatment and care I received at every level throughout a two week stay. I was tube fed, had five days of IV Immunoglobulin and the inevitable introduction of increasing steroids (Prednisolone) which eventually kick started all those failed muscles. I worked hard to aid my own recovery and have I hope established a relationship with the hospital which in conjunction with the MGA will allow me to offer support for other sufferer's of myasthenia.

Having made the 'transition' from ocular to generalised in a radical way over a short(ish) time has certainly changed me as a person in many ways, although I know what lies ahead, I refuse to live in fear of it. Like many of you, I have suddenly had to adapt myself to complex medication when I would normally avoid even a paracetamol for an headache.

I now consider myself fortunate, I have a very understanding and loving family, many caring friends and faith in the medical support I'm receiving..... All I really need now is another holiday but maybe not in..... You guessed, Bridlington.

Brian Murphy, Birmingham





Giving Back to Those That Give

On 15th February 1994, when she was 14, Amy Guy (previously McIntosh) was diagnosed with Myasthenia Gravis.

It will be 20 years on 15th February 2014 since Amy was diagnosed with Myasthenia Gravis. To mark this occasion, Amy and her family, decided it would be a good idea to raise awareness of her condition. Amy came up with the name "Amy's H.O.P.E. 20", to use in fundraising leading up to the anniversary of her diagnosis.

The fundraising has already begun, in the form of selling at car boot sales, baking cakes and selling them at local gatherings that they attend, and raising sponsorship for a Skydive, which Amy's brother, sister-in-law, and mother undertook on Sunday 6th October 2013.



Photo above shows Sue, Jay and Bridget after their brave skydive

The Main Event

Afternoon Tea at Lyndhurst Park Hotel, Hampshire on Saturday 15th February 2014

Amy wants the main fund raising event to reflect some of her loves, which is how the idea of an Afternoon Tea at Lyndhurst Park Hotel came about. After all, who doesn't like cake!! The afternoon will include more of Amy's loves, including music, dance and art.

There will be entertainment throughout the afternoon with displays of Zumba and Street Dance, there will be music provided by a local easy listening band (The Joker and the King), others to be confirmed, and members of the local Rock Choir. There will also be Table Magic, an Art Auction with donations from local artists and a Prize Draw with many prizes donated by local organisations and companies. A local DJ will host the proceedings.

Tickets for this event are now available at £18.50 each. Each ticket will be entered into a draw to win an overnight stay and dinner for two at the Lyndhurst Park Hotel at a later date.

For more information contact: Amy Guy Telephone: **07709 193718** or Email: **ami.megan@talktalk.net** Kim Nicholls Events Organiser Telephone: **023 8028 3923**

Amy is also writing a book giving both a light hearted look at life with Myasthenia Gravis, as well as some of the more serious aspects of how it has affected her. The book has also had a bit of input from those close to her, including her PAs, her mother and both her daughters. Hopefully the book will be available by 15th February.

All money raised will be divided between the Myasthenia Gravis Association and the Stanley Graveson Ward Wessex Neurological Centre, Southampton General Hospital.

Ken Poole

Ken Poole passed away suddenly on 3rd September in hospital aged 86. He was a much loved husband to Betty, also a dear dad and granddad.

A private cremation service was held at Ollerton followed by a Thanksgiving Service at Grove Street Methodist Church Retford.

As many of you will know Ken was our branch secretary for many years until his retirement in 2008. We all enjoyed his company and he always had a keen sense of humour. Ken also served on the board of trustees from 2001 to 2002.

I'm sure he will be missed by all.

Barry Gregory, Chair Yorkshire (South) Branch

Joan Packard

It is with great sadness that we announce the death of Joan Eileen Packard in May this year.

Joan was a member of the Suffolk branch and had been diagnosed with MG when she was in her 30's in the 1950's. She passed away peacefully at the age of 92.

Joan had a successful thymectomy in 1953 whilst under the treatment of Sir Geoffrey Keynes; at the time the doctors had no idea what the outcome would be, but she was fortunate to have a complete remission and lived a full healthy life without the need of medication.

Maria Martin, Regional Organiser

Tom Ellis

It is with regret that I have to report the sudden death of Tom Ellis from Durrington in Wiltshire, a family friend of 35 years who had MG for the past two years.

Tom spent his early years on the Belvoir Estate before going into the Navy – about which he had many stories to tell on our journeys to and from MG meetings. He then took on the

job of 'water keeper' for the Piscatorial fishing club in the Woodford Valley and this is where we got to know him.

Tom found MGA a real life saver when he was diagnosed as he felt he was the only person with this disease. Once he had attended meetings and met others in the same boat as himself he was able to adjust and realise he was not alone. We will miss his company at our Wiltshire meetings but we know that the charity was there for him when he needed it.

Bob Goldthorp, Member Wiltshire Branch

Christine Pye

It is with great sadness that on 7th September 2013 the members of the Essex South branch were informed of the death of Christine.

Christine and Allan her husband were founder members of the branch, in fact Allan was the first chair of the branch. Allan and Christine worked hard through the years on fundraising events.

Christine was treated for congenital Myasthenic syndrome at the John Radcliffe hospital and took part in many trials.

We will miss Christine at our branch.

June Thynne, Secretary Essex South Branch



FEEDBACK

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

The opinions expressed are entirely those of the contributor. Care should be taken if following any advice or suggestions presented and it is strongly recommended that the advice of your GP or Consultant is taken in all cases.

Please Note: MGA reserve the right to open any letters which are sent to MGA to be forwarded on.

This is to prevent the recipient being upset by receiving unsuitable mail. Email addresses are withheld to prevent Spam.

Please send email enquiries to mg@mga-charity.org and we will forward them on.

Dear MGA,

I would like to congratulate my grandparents, Francis and Audrey Harmsworth, who celebrated their 60th Wedding Anniversary on the 29th August 2013. Francis was diagnosed with myasthenia gravis last summer when suffering with eye, throat and breathing problems. This came as a shock to the whole family, who had never heard of myasthenia gravis before. A difficult year of tests and medication followed, but MGA provided a lot of essential help and information. Francis' symptoms have now improved and he is learning to live with MG. Thanks to everyone at MGA for their support and to Natalie James at The National Hospital London for her advice.

On the day of their anniversary, Francis and Audrey had a reunion lunch with family and friends. They asked people not to give them presents, but to make a donation to MGA instead.

In the past year, I have raised £1,298 for MGA through various initiatives, such as a Zip Slide across the Oval, cake sales, raffle tickets and money donated by my employer from its charity bookshop. I would like to thank my colleagues at Hodder Education and my employer Hachette for their generosity, as well as Rita Goldthorp and Steve Saunders, who have been my fundraising contacts at MGA.

Chloé Harmsworth, Hertfordshire

Dear Editor,

Please find enclosed a cheque for £340. The proceeds of a coffee morning held at my parents house—Janet and Ken Brook in Sprotbrough, Doncaster.

A massive thank you to them and my sister Jackie Feasey for all their help and hard work. I would like to say thank you to everyone else who helped and to everyone who came and gave so generously.

Yours sincerely

Kath Millis (Myasthenia Sufferer)

Dear MGA,

Please find enclosed cheques for the total of £250 as the result of donations received at my husband John's 70th birthday party. John asked for donations to be made to MGA instead of birthday presents.

Thank you for sending the information that we could give to friends.

A good time was had by all!

Yours sincerely

Joyce Rymer, Gloucestershire

Dear MGA,

Helping people like mum

On 8th September 2013 I went off to Dunkerswell in Somerset with my partner and four year old son to do a sponsored Tandem Skydive in order to raise money for MGA.

It was an awesome experience and I would love to do it again. I raised £288 for the charity which will be further enhanced by funds that were gift aided, and also raised awareness of myasthenia through local newspaper articles.

My mum was very ill when first diagnosed three years ago and I am so pleased that she is well again now.



Best wishes,

Beverley Miller, South Wales

ISLE OF WIGHT

Good morning, this is your Captain speaking, 'welcome aboard 'Wight Sun'.

This was the welcome received by branch members and friends at the start of our first on-board collection with Wight Link Ferries, route, Yarmouth – Lymington. Luckily, it was a relatively calm sea, good weather and the start of the school holiday rush to the 'Garden Isle'.

The only down fall was that duty free goods weren't available!!!

£183.50 was collected whilst on board and both crew and passengers were very interested to hear all about MG. We would like to thank all staff within Wightlink who made this collection possible.

Our 'In Store' charity collections were held again during the summer months to catch the 'captive holiday makers' and thanks to the customers of Morrison's, Lake, Co-op, Freshwater and J. Sainsbury's Newport. The branch managed to collect £567.36.

In addition, Roger and Lynne were given a donation of £200 by Michelle and Tim of 'The King's Head', Yarmouth, some of the proceeds given to local charities from the Sunday night quiz evenings held during the year.

Michelle & Tim think of us (MGA) as a local charity, which is brilliant and we appreciate this very much.

The branch is very lucky with the support and recognition received to date on the island and takes this opportunity of thanking everyone who has helped and supported us over the year.

Finally, we would like to close by saying that our Publicity Officer gave a talk on 'MG, Not just a famous car but.....' to people including some professionals, who attended the 'Living



with Long Term Conditions, Drop In Café', held at West Wight Sports Centre, early October. The talk and power point presentation was well received and was followed by a question and answer session during which all admitted that they had never heard of MG. It was well worth the (almost) sleepless night prior!

Well, like the red squirrels, we will go into hibernation until the spring but we are busy planning for next year.

Thanks to all at MGA for their continued support and help.

Lynne Pitcher, Publicity Officer

HAMPSHIRE BRANCH

Cyclists in Saddle for MGA

On Sunday morning the 9th June it was sunny in Liphook and just the right temperature for cyclists to begin the LiDBA 25 mile journey around the beautiful lanes of Hampshire and West Sussex.

It was the fourteenth consecutive year that the Hampshire branch of MGA had entered a team. Through sponsorship money we have raised over £28,500 for MGA in those fourteen years. The final amount raised this year was £802.50.

We were delighted to welcome in our team this year four cyclists from Tangemere in West Sussex. One of them heard about the event from his Mother living on the Isle of Wight, who has MG. We have riders living in London, Basingstoke and Andover taking part, distance does not appear to be a problem to cyclists!

With cycling being so popular, we hope that many of you will join the MGA team next year on **Sunday June 8th 2014. You can register now by phoning 01428-776467.**

The riders always comment on the attractive countryside and how well LiDBA (Liphook & District Businessmen's Association) organise the event.

Joan Finney, Branch Secretary

Young MGA (NATIONAL) BRANCH

The very first Young Myasthenia national event was held on 7th September in London. With just under 50 people in attendance, travelling from all over the UK, it was a fantastic and informative event.

Our specialist speakers certainly gave many people food for thought and the social dinner in the evening gave people the chance to mingle further and make new friends. It is hoped that we will be able to set up satellite groups throughout the country to meet up regularly like the London group does. And plans are in place to get funding for next years event, which we hope will be in the Liverpool area.



If you want more details of the Young Myasthenia group (ages 18-45) please take a look at our Facebook page www.facebook.com/YoungMGA or contact maria.martin@mga-charity.org

Maria Martin, Regional Organiser

DEVON NORTH BRANCH

Members of the Devon North branch held a market stall in South Molton raising £175.



While manning the stall they were presented with a cheque for £200 from the Rotary Club of South Molton to support MGA work in North Devon.

Photo above show cheque presentation.

Rita Goldthorp, Regional Organiser

ESSEX SOUTH BRANCH

We have had some fundraising at the branch this year. A BBQ in May at our chair Paul and his wife Jane's house raised £50.

In June an Afternoon Tea was held at the secretary's house raising £195. Also in June Michelle Billot raised £225 by holding a fashion show at M & Co clothes store in Wakefield.

As their charity of the year, The Club North Harrow Evening Townswomen Guild raised £500 for MGA.

In August one of our members Vincent Mooney walked up Mount Snowden to the summit and back down and raised £210.

June Thynne, Secretary

LONDON (CENTRAL & NORTH) BRANCH

Interested in walking on Fire!?!

I am planning on organising another exciting firewalk in the New Year in North London. If you would be interested in taking part, please contact me for more details. All arrangements still taking place as we go to press but it will be a Sunday evening, probably late February early March. For further details contact maria.martin@mga-charity.org



Cocktails & Cabaret is back already!

Due to the fantastic night we had on 24th October, we are already planning another Cocktails & Cabaret on Wednesday 12th March.

If you couldn't make the last one then make sure you don't miss out again. Tickets are just £15, which includes a free cocktail and a fabulous night of entertainment. The venue will be The Loop Bar, off Oxford Street and tickets can be purchased at



www.justgiving.com/cocktailsandcabaret

Maria Martin, Regional Organiser



RO North West & North Wales

Sarah Sanders

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We're delighted that the Bury, Rochdale, Oldham and Salford branch is now up and running and meeting at the Demesne Media Arts Centre in Middleton. Pictured below are the members with Karl Parr, Rachael Robinson and Jim Dobbin MP for Heywood and Middleton.



Many thanks to Jessica and Katie Robinson (pictured below) for taking part in the Arley Hall 10km in support of MGA member Lynne Holt also pictured below. The girls managed to raised a fantastic £515 in sponsorship!



Thanks to everyone involved in making our annual regional conference a success! We were delighted to hear a very useful and informative presentation from Dr Geoff Keir from the Immunology lab at the Walton Centre in Liverpool.



Scotland

Lynn Stewart

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Family Matters

Lesley Hart participated in Pedal for Scotland and raised the wonderful total of **£279** for MGA. Lesley's Aunt, Jessie Young, suffers from myasthenia and is a member of Strathclyde branch.

Isabel Nesbit who suffers from Myasthenia, organised a fundraising event for MGA, with the support of her family and friends. Fifteen of Ayrshire's finest musicians played a sell-out gig, at Ardrossan Bowling Club, raising the tremendous total of **£900**.

SUPER Markets! Waitrose Community Matters Photo below shows Graham Black, Deputy Manager of Waitrose, Morningside, who presented a cheque for **£355** to Lothian branch secretary Nigel Marcel and Lynn Stewart Regional Organiser.



Tesco Collections - A collection in Tesco Crieff Road Perth, raised the fantastic total of **£178.99**. Thanks to Marjory and Jan who raised the terrific total of **£191.06** in Tesco, Alloa.

ASDA Chesser Community Life Fund



Photo shows Linda Anderson from ASDA, Chesser who presented a cheque for **£50** to MGA, Lothian branch secretary Nigel Marcel.

Stalls Tom and Eileen Gibson had a stall in aid of MGA at a Farmer's Market in Lanark, they raised an amazing total of **£179.01**.

Christmas stalls in aid of MGA were held at Wishaw General Hospital on 27th November and 4th December.

Life with Art – venues & dates in Scotland to be confirmed.



South East

Steve Saunders

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MGA chalked up another success with the very first **118 118 Fun Run & Walk** to be held ever – anywhere! Our fun-loving participants were kitted out in curly wigs, moustache and

118 runners number to mimic the famous characters from the 118 adverts. This new fun run was held along the seafront in Bognor Regis



and covered a distance of about 2.5 miles from West Park, Aldwick to Butlin's and back with prizes for the best dressed 118 runners as well as the highest fundraisers. Close to £3,000 was raised by all those taking part which was a magnificent effort for this new fundraising event so well done and thanks to all taking part.

Three of our **local branches** in the South East held their annual branch walks at Seaford in Sussex, Margate in Kent and Fareham in Hampshire. Thank you to those taking part again this year and between them £2,500 has been raised to help the branches carry out their local work!

All of our local branches are always on the look-out for new members and can be a source of great help for many myasthenics, particularly during the scary first few weeks and months after diagnosis so please let me know if you would like to be put in touch.

WHY RUN WHEN YOU CAN WALK?

Registration is now open for our annual walk of the official London Marathon route which will be taking place on Saturday 5th and Sunday 6th April 2014. Walkers will be covering 13 miles each day with full back-up and support, before finishing with a celebration reception party at the finish on the Mall. For more information e-mail **steve.saunders@mga-charity** or call Steve on **01273 581087**.

Arrangements are under way for an exciting new abseil event to be held near Gatwick in West Sussex with the exact venue soon to

be announced. This will be first abseil event we have held for a couple of years now in the South East and demand is sure to be high. If you are interested then please get in contact now and you will be one of the first to go onto the waiting list once details have been finalised for this new event to be held in early 2014. E-mail me at **steve.saunders@mga-charity.org** or call **01273 581087**.

Lastly, enormous thanks to all of our supporters and friends for helping to make 2013 another great year for MGA and we wish you all a Very Happy and Prosperous New Year!



Midlands

Anna Pitt

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Our friends at Park Hall Academy are supporting MGA again with a series of whole school assemblies focusing on raising awareness of MGA. The week of assemblies will culminate in a non-uniform day for students, and the school are hoping to raise in the region of £1,000 for our charity. If you have a connection with a school, why not put us in contact with them – assemblies are a great way for us to raise awareness, and school fundraising is a valuable help to us. Thanks again to the staff and students of Park Hall Academy, Castle Bromwich for their on going support.

October saw MGA as one of the chosen charities for Waitrose in Mere Green, Sutton Coldfield. The money raised will support the local branch of MGA in Birmingham. So don't forget, if you have a local branch of Waitrose, why not pop in and fill in one of their 'Community Matters' Forms to nominate MGA.

On 20th October, 3 MGA supporters took part in the Great Birmingham Run (a half marathon around the second city). Our thanks to those who continue to put in phenomenal physical efforts to support those who aren't able to.

In 2014 MGA are delighted to be the chosen charity for Franklands Insurance in Derby. We are looking forward to working closely with them to raise awareness and funds throughout Derby. Does your employer operate a Charity of the Year Scheme? If so why not let us know and we can get in touch.



Greater London & East of England

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A Night of Musicals – Sunday 9th February

Following the stunning success of A Night of Musicals last February, we are arranging another for 2014. Featuring some wonderful singers from the West End stage and some firm favourite tunes, don't miss out on your ticket to this fabulous event. The venue is being currently finalised but it will be central London. Tickets are just £20 (this doesn't include any food or drink) but if you came along before, you know it is well worth the money! To purchase your ticket please go to www.justgiving.com/mgamusicalnight

Why Run When You Can Walk

Taking place on 5th/6th April 2014 is our 5th annual Marathon Walk Event. You've probably seen this event advertised many times before and not given it a second thought, but why not think about it now? If you can't walk 26 miles, and we know many people would find this difficult for obvious reasons, why not get your friends or family to do it on your behalf? It's a great way to raise money for your favourite charity and a brilliant sense of achievement when done. So take a look at our website www.mga-charity.org/marathonwalk or contact Maria on **01277 621 643** for further details.



South West

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Branches around the Southwest and South Wales have been really busy over the summer with meetings and fundraising events.

The Cornwall branch invited Colin Stevens to their meeting in Bodmin to demonstrate how Tai Chi could help those with MG. "I'll go but I can't see that it will do much good" was one comment from a member who after the event said "Can we raise the funds to invite him back again? That was fantastic – he really understood us and our limitations and provided a programme of exercise that we can manage".

Colin has been invited to attend a meeting in Teignmouth with the Devon South branch

and also the regional meeting in Weymouth on 19th March so do come along and find out more.

The Somerset and West Dorset branch have been very busy fundraising for a cough assist machine for Poole hospital. Events have included a quiz night, bingo night and a Christmas stall in Bridport. They have also been given a £200 donation from the Oddfellows which will support their costs. Funds given by Awards for All will help to provide interesting projects and days out for their members and the first of these will be a photography day at the National Trust garden at Stourhead where they will take photos to make a calendar.

The 3 Counties branch linked up with the Wiltshire branch to provide a day out for their members to Highgrove, the home of their Royal Highnesses Prince Charles and the Duchess of Cornwall. It was a wonderful day which everyone enjoyed and the guide was very good making time for those in wheelchairs and the need to take rest. The branch would like to organise another trip for the spring to see the wild flower garden and they welcome enquiries for this event.

The Bristol, Bath and North Somerset branch have been busy with their Tesco collections and regular support meetings. The members were very keen to support the Ocular MG month and took lots of leaflets around to their local opticians.

Members in Devon have been busy with a stall at South Molton market which raised £175 and donations from local trusts to support our work in the area. Market stalls and store collections are a very good way not only to raise funds but also to raise awareness. We often find that people with MG/CMS who had no idea that we existed will approach us at these events and become members.

Do YOU know anybody who might be interested in walking the Freedom Trail across the border from France to Spain next July? This is the route taken by allied servicemen and Jews to escape from the Nazis – it is arduous and you need to be fit to take part. There are many plaques along the route to those who died trying to escape and you even pass a crashed Halifax bomber. This week long guided trek will be a very different way to take your holiday. The deposit is £149 with a minimum sponsorship of £1,800 of which MGA will receive £900. The cost includes flights and most meals and accommodation.



Northern Ireland

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MGA Information Day September 2013

On 11th September MGA held an Information Day at Corr's Corner Hotel, Templepatrick. The event was funded by the



Big Lottery and enabled MG sufferers and carers from across the province to meet up with old friends and meet some newly diagnosed patients. The speakers on the day were Caroline Carmichael, Specialist Nurse, Siobhan McCauley, Neuro Physio and Pascal Benson, Alternative Therapist. Martin Rogers welcomed everyone to the event and made everyone feel very involved and able to engage with the speakers.

All those attending thoroughly enjoyed the day and found it very informative. Sheree Brown the new Secretary of the Belfast branch was congratulated on a great venue



and everyone particularly enjoyed the delicious lunch, kindly funded by the Big Lottery.

BBC Radio Ulster Broadcast Appeal

MGA has been featured in a BBC Radio Ulster Broadcast Appeal. The appeal was heard by approximately 150,000 listeners and featured MG sufferers and medical practitioners in Northern Ireland. This appeal is a wonderful opportunity for MGA to raise the profile of Myasthenia and the support services on offer to patients and carers. The radio appeal features Bill Wolsey who presents the appeal and introduces Joan Emery and Heather McCarroll who talks about her son Tom. Their stories are very compelling and really highlight the different experiences of MG sufferers and their families.

In addition to the radio appeal the BBC Appeals Website features interviews with

John McConville Consultant Neurologist, Julie McDowell Optometrist as well as MG sufferers Bill Wolsey, Rev Jim Rea and John Coulter. Please take this opportunity to go onto the website and listen to the interviews

<http://www.bbc.co.uk/northernireland/community/aac/appeals/mg.shtml>

CHRISTMAS SHOPPING FOR MGA



Ireland

Karen Clancy

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00353 65 6838 270

Email:

karen.clancy@mga-charity.org

It's not too late to pick up **last minute gifts at great prices** in our online charity shop.

Stocking quality cards and gifts from just a few Euros with low shipping costs – this is a great way to **support your charity** and get a bargain at the same time! Our online shop securely accepts Paypal – but **you don't need a Paypal account** – just a credit card. Alternatively if you see an item you like you can **order by telephone**. We'll be shipping right up until Christmas – while stocks last! **www.mga-charity.ie/store**

WANT TO TRIP THE LIGHT FANTASTIC?

Ever wanted to glide around the dance floor 'strictly style'? Now's your chance! We will be **recruiting future dance stars for a 'Strictly' fundraising event** to take place in the spring. The event will include special dance training and the dance-off in Dublin. We will be looking for **13 pairs of guys and girls to take part** (not necessarily couples) – if you think you have what it takes – get in touch with Clare at **clare.foley@mga-charity.ie**

OMG – ABSEIL EVENTS

To help to continue to raise awareness for **Ocular Myasthenia** we are organising **fundraising abseils** – locations will depend on numbers – if you're interested in having a go at this **adrenaline packed activity** contact Clare on **clare.foley@mga-charity.ie** and we can send you more information.

Don't forget you can keep up to date with our regional news, events and updates via our facebook page – you can find us at **www.facebook.com/mgaireland**



North
Linda McDonald
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Lots of thanks go to

Claire Piggott, daughter of **Les Waby** from York, who took part in the York 10k and raised £150



Annette Phillips from Cumbria; to all the runners from our region who took part in the Great North Run – **Chris Jackson, Emily Hill, Lyn Dayson, Carole Boyle, Susan Clark, Peter Coyle, Christopher Goossens and Max Applegarth** and also, running to support the Myasthenic Kids Branch, **Beth Cockburn, Stuart Tait, Kayleigh Pearson, Mark Turnbull and Gary Wilson** – you may not have been up at the front with Mo

Farrah but you are all winners as far as we are concerned to **Richard Cowan, Rachael Cowan,**



Anne Booth, Alan and Julia Young, Graham Haman, Paul Fenton and Paul Jackson who took part in the first Why Run When You Can Walk event in our region and walked from Newcastle to South Shields, following (almost!), the route of the world's most famous half marathon. We plan to stage this event again soon (now that the route has been tried and tested) so if you would like to take part please contact Linda; to **Janet Chappell** from the South Yorkshire Branch who had a stand at the Doncaster Lions; to **John and Rose Kozyra** from Leeds Branch who held their Annual Square Dance in Harrogate; to **Frank and Joan McLean** who organised a stall and raised £500 for the Leeds Branch.

On Sunday, 29th September, at the Holiday Inn in Wakefield we were joined by 76 members

for the **Yorkshire Regional Conference**, where our excellent speakers included **MGA CEO Ruth Ingledew and Dr Jennifer Spillane** from the Royal Free Hospital in London. We were delighted to be joined by footballing legend, ex Leeds United player, **Norman Hunter** whose daughter Claire has MG. Norman was presented with a Gold Rag Doll Award for his exceptional support.

Calling all fun runners, runners, walkers and thrill seekers!

Fun Runners get in the Christmas spirit and take part in or come and watch our **Santa Fun Run on Sunday 15th December at Temple Newsam Park in Leeds** starting at 10am. Thanks to Julia Littler for all her help in organising this event.

Runners please sign up to take part in the 'Friendly' **Sheffield Half Marathon on Sunday 6th April**. MGA is proud to be a benefitting charity from this event. It's a flat and fast course and you are assured of a friendly reception from the volunteers and from the crowds on the streets. Please ask your family, friends and work colleagues to take part for MGA. Enter online at **www.sheffieldmarathon.com** or contact Linda for an entry form.

Walkers, we need you to be part of a 100 (minimum) team to take part in the **Yorkshire Three Peaks Challenge on Friday 15th August**. Entry fee is just £25 (but we need 100 people) and includes free training walks. Walk 24.5 miles in 12 hours in this challenging endurance experience in the Yorkshire Dales National Park with some of the most beautiful scenery in the UK. With everyone walking for MGA it will be a day to remember. We also need volunteers on the day. Get a team together – family, friends, work colleagues and sign up now!

Thrill seekers, now is your chance to sign up for the **Awesome Foursome** (Zip Wire / Abseil / Powerfan / Bungee) at the Abyss at Magna in Rotherham. The Abyss has created a unique experience for thrill seekers. Set in semi darkness complete with music, video screens, dry ice and effect lighting, four exhilarating activities utilise the breathtaking facilities and structures of this former steel works, providing a truly dramatic backdrop for the ultimate in adrenalin experiences.

For more information about all the events please visit **www.mga-charity.org** or contact Linda on **01325 308180**

Lottery Draw Winners Autumn 2013

Position Prize Value Winner

1st	Mr R Drummond, North Yorkshire	£1,000.00
2nd	Mrs J Evans, Middlesex	£350.00
3rd	Mrs Haylock, Cambridgeshire	£150.00

McPherson Draw Winners

Draw August 2013

1st	Mrs J Green, Bristol	£79.25
2nd	Mrs J McCulloch, London	£47.55
3rd	Mrs F Green, Kent	£31.70

Draw September 2013

1st	Mr K Jones, Ceredigion	£76.25
2nd	Mrs S Taylor, Kent	£45.57
3rd	Mrs R Bowden	£30.50

Draw October 2013

1st	Mrs R Brookes, Derby	£75.75
2nd	Mr L Galloway, Devon	£45.45
3rd	Ms T Luetchford, Kent	£30.30

Congratulations to all the Winners

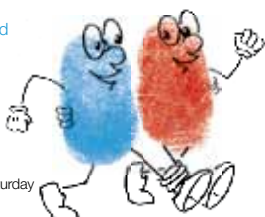
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We have worked with the Myasthenia Gravis Association and insurers, so that those affected by myasthenia gravis, and all pre-existing medical conditions and disabilities, can access comprehensive and competitively priced insurance.

For more information please visit www.mga-charity.org
Alternatively, call the Unique team on **01603 828359** (quoting MGA News).

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Merry Christmas and Happy New Year from all at Unique

It's not always easy to get insurance when you have a condition, and Unique are understanding and know what they're talking about, ensuring you feel no prejudice in that situation - it shouldn't be impossible to travel, it just means you take extra care. The service was fantastic, and gave me peace of mind.'

Lynda, East Sussex

Christmas is a time for family, and the New Year for thinking of the future. For many of us, our thoughts turn to resolutions, making plans and thinking about what we can do differently. **Unique in partnership with MGA** may be able to help with your financial planning, both for you and your loved ones. We offer a range of products that may put in place a more secure future for your family...

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- protecting your family too, should you no longer be there for them - Leave your family with a cash lump sum if you die - Protect payments that your loved ones may need to make - Amount of cover to suit your needs - Affordable premiums

It may be you already have a life assurance policy in place with another provider? That's okay, it's important to keep that in place, but you can still apply for additional cover through **Unique**. Increased age and changes in medical circumstances may mean that being accepted for cover is more difficult and it could be the right time to come to us.

Find out more about all of the above by visiting www.mga-charity.org

Have your own **Unique** experience and call the friendly team with that personal touch today, on **01603 828 359**. **Remember, for every policy sold we make a donation to MGA, and at no additional cost to you.**

Also for Travel, Home and Motor insurance

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IMPORTANT INFORMATION

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Lisa Joyce
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Southampton 02381 205948

Caroline Carmichael
Southern General Hospital
Glasgow 0141 232 4022

Benefits Officer Email: benefits@mga-charity.org

Recycle your print cartridges and mobiles and raise funds for MGA.

Contact RECYCLE4CHARITY on 01273 400 185
or email: info@recycle4charity.co.uk

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Receive our periodic E-News
and get updates about Myasthenia, events and
news. Just sign up at
www.mga-charity.org/newsletter

MGA Forum

Join our online community, where you will find advice, information and peer support 24/7. Share your experiences and advice with others. Ask questions and learn more about myasthenia from fellow sufferers from all round the world. Make new friends without leaving your armchair. Start your own blog about your experiences, read other myasthenics blogs. Chat online in real time with your fellow MG forum friends. All this and more available now. Log directly onto www.mga-charity.org then click on forum.

Help Lines:

UK: 0800 919922
Ireland: 1800 409672

We're on the WEB

www.mga-charity.org
www.mga-charity.ie

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