



Hampshire Branch Newsletter

November 08

Seasonal Greetings

We wish all our members the very best for Christmas and the New Year.

2008 has been a fantastic year for the branch both socially and financially. Many members have organised their own events, which has increased our funds and improved the awareness of MG across the county. There have been more members at events, in particular The Gosport Walk and the Regional Conference. We have sent more money to HQ than we have in previous years at this time; the financial year does not finish until the end of March.

MGA in Hampshire could do *even better* if more of you supported branch events and helped us to create new branches in the county!

Committee

Chairman: Brian Openshaw

Secretary: Joan Finney

Treasurer: Alan Whitehead

Welfare Officer: Jackie Perry

Minutes Secretary: Barbara Whitehead

Member : Irene Jenkins

Member: Barbara Openshaw

Member: Baldish Mandair(Bali)

Editor Joan Finney

RO Steve Saunders

Future Events

CHANDLERS FORD

CHARITIES MARKET

SATURDAY NOV. 8TH 9.30 - 12.00

Methodist Church Hall, Fryern.

Monica and Andrew Moore will have a MGA stall at this event. Anyone in Chandlers Ford who would be willing to make a cake or provide produce for the "Cake" stall, please ring 023 8025 3578 to arrange delivery.

BLISS FAIR

HASLEMERE HALL

SATURDAY 15TH NOVEMBER

9.00-1.00pm

If you have any new or nearly new items suitable for my Christmas stall please contact me. I am also collecting small items for the children's lucky dip. *Contact Joan Finney 01428 776467*

CHRISTMAS FAIR

HEADLEY VILLAGE HALL

SATURDAY 29TH NOVEMBER

9.00-1.00PM

At this event I sell woollen goods, knitted by a good friend of mine. This is the third year of having this stall and the same customers return knowing that I sell good quality items.

If there is anyone willing to knit items for the stall in the future, I would be pleased to hear from you. Also, I am most grateful for donations of wool.

Contact Joan Finney 01428 776467

Fund Raising

The last Newsletter summarised income received up to the bank statement dated 31st December. In the 3 months to the financial year end, March 08:-

Donations

Mrs H M Miles
Mr & Mrs M J Mullens
Mrs S Lowe
Mr & Mrs R Soar
Mr D J Woods
Mrs K Sills
Mrs P Jones
Mrs Bull

TOTAL £ 204.57

Events & Collections

£ 224.70 Mrs J Perry (Coffee Morning)
£ 408.00 Tesco Southampton
£ 292.00 Bridge Afternoon

Collection Boxes

£ 16.54 Gables News, Liphook
£ 114.32 The Greyfriar, Chawton
£ 31.00 Carol Moore
£ 7.56 Swinburne Motors

Other Income

£ 10.00 Sale of cards by Mrs Suzi Shafir
£ 12.70 Card sales by Mrs M Moore

As at the year end Bank Statement (to 31st March 2008) the Balance stood at £967.31 and a further £1000.00 had been sent to Derby, making a total of £ 7000.00 for the financial year.

We have had a very busy 6 months from the start of this financial year April 2008.

Donations

Mrs HM Miles
Mr C Terry

Chichester Round Table & Ladies' Circle
(£1000.00)

Chandlers Ford Scouts (£ 108.12)

Rotary Club of Southampton East (£ 250.00)

Scottish Southern Energy (£ 750.00)

TOTAL £ 2165.121

Events & Collections

£ 115.00 Coffee Morning (Mr & Mrs A Moore)
£ 290.00 Haslemere Charter Fair
£ 237.19 Petersfield Collection
£ 60.00 LiDBA Stall
£ 215.30 Coffee Morning (Mrs J Perry)
£ 275.00 Tesco Bursledon
£ 481.11 Coffee Morning (Mr & Mrs R Soar)
£ 234.03 Hedge End Collection
£ 314.94 Stubbington Village Fair
£ 392.00 Tesco Southampton
£1557.33 World Walks

Collection Boxes

£ 17.78 Gables News, Liphook
£ 127.33 The Greyfriar, Chawton

Other Income

£ 16.00 Sale of cards by Mrs Suzi Shafir
£ 44.00 Card sales by Mrs M Moore
continued

As at 30th September the Bank Balance stood at £2352.02 and £5000.00 had been sent to Derby. This compares with £ 7000.00 for the previous 12 months and we have 6 months to go!

This is a splendid effort, brought about by hard work of your committee and those enthusiastic members who have organised their own events. Credit is due to Steve Saunders, the Area Organiser for the SE Region who has worked tirelessly. We are most grateful for all donations received and special thanks are due to Mr A & Dr M Campbell for the donation from Chichester RT and Ladies' Circle, Mr P Exley (Southampton East Rotary Club) and Mr C King (Scottish & Southern Energy).

With income from the LiDBA Bike Ride still to come, I expect to be able to report our contribution to Derby to total at least £10,000.00 by the financial Year End.

Alan Whitehead Branch Treasurer

Reports

On Wednesday 30th July a coffee morning was held at the home of Reg and Marion Soar. It was a glorious day and the event raised £481.11. Many thanks to Reg and Marion and to all the helpers who made it most enjoyable for all those who attended. *Brian Openshaw Chairman*

August Bank Holiday Monday saw us once again with our usual stall at the Stubbington Fayre and Donkey Derby raising £314.94 for MGA. Thank you to everyone who helped and gave donations. *Barbara Openshaw*

Thanks are due to Jackie Perry who has managed to arrange several collections at Tesco Stores in Southampton. She has also had two coffee mornings all of which has certainly raised a lot of money for MGA.

I am delighted to report that this year 38 riders took part in the LiDBA Cycle Ride. I know they have collected over £2000 from sponsors and next week I shall be told the final amount from LiDBA. *Joan Finney Secretary*

HAMPSHIRE NEUROLOGICAL ALLIANCE

Myasthenia Gravis is a rare disease affecting around 1 in every 7000 people. But how many people in the UK have a neurological condition? 10 million of us and that's 1 in 6!

The Neurological Alliance is a wide range of neurological charities which have come together to make life better for people in the UK with a neurological condition. Its aims are to:

- Raise awareness of neurological conditions and their impact
- Inform and influence policy makers about the needs of people with neurological conditions
- Secure the highest standards of service and improved care for people with neurological conditions
- Promote research and the dissemination of information about neurological conditions

The Hampshire Neurological Alliance (HNA) is the sixteenth and latest branch of the Alliance, and the Hampshire Branch of MGA was in from the beginning. Its mission is to influence decision making by the service providers to improve care and support for all people affected by a neurological condition. There are currently 14 charity members in the HNA and, it is hoped, others will join. The HNA is already working with Primary Care Trusts and the County Council and links are established with MPs and the Strategic Health Authority but it is still at a formative stage and needs strengthening. In a recent letter to members the Chairman, Professor Brian Eyre said "This could take the form of joining the Committee or to take part in implementing specific projects either individually or as part of a small task force. Are there any volunteers to join in this effort? People interested in following this up can contact me to discuss where we need help and what you can do." He stressed financial support was available to pay travel expenses etc incurred in carrying out the work. Brian can be contacted at brian.eyre@materials.ox.ac.uk

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or by telephoning the HNA Secretary, Belinda Williams on 01425 659890.

An important date for your diary:

It is planned that the HNA will be officially launched at the Discovery Centre in Winchester on 16th March 2009

Alan Whitehead representing the MGA on HNA.

SE Regional Conference Liphook

A total of seventy six people attended the conference, from the branches in Kent, Sussex, Woking, Berkshire, Surrey, the Isle of Wight and Hampshire.

The Regional Organiser Steve Saunders opened the proceedings. He spoke about events that he had organised in the past and would be repeated in the future; such as Guy's Hospital Abseil, Walks for the World Walk Campaign, Super Heroes Fun Run, and Santa Fun Run at Eastbourne. He asked for members and their friends to take part to help MGA. Volunteer speakers for the School Bulbs Campaign and cyclists for the LiDBA Cycle ride would also be welcome. There was a need for more branches and although a new branch was opening in W. Kent there was a requirement for more in the other counties in his area. Steve can be contacted tel. 01273 581087 E-mail steve.saunders@mga-charity.org

The morning session continued with the Chairman of MGA, Mr Peter Finney, discussing matters about the association. He said that the Treasurer and Finance Committee had done their best to secure the reserves of the association that is required to finance research and education. Specialist MG nurses were working at hospitals in Oxford and Liverpool and negotiations were in progress with NHS Trusts in Glasgow, Belfast and Southampton for more MG nurses. MGA was financing a three year fellowship for a post-graduate student leading to a PhD, and another one was in negotiation. Professor David Beeson was being supported by 50% for his research into Congenital Myasthenia. Lastly he reiterated Steve's plea for more branches, as at least 1,319 myasthenics known to MGA were not in a branch; the association needs members to create more branches.

In the afternoon Dr Ashwin Pinto, consultant neurologist at the Wessex Neurological Centre Southampton General Hospital, gave an informative talk about MG. He explained what goes wrong at the nerve and muscle junction. He then outlined the treatments available. Depending on the patient, he preferred the long term treatment to be steroids with a sparing agent (Azathioprine) rather than Pyridostigmine (Mestinon). Unfortunately, many of the drugs need more trials to assess their value. This requires a lot of patients to take part and costs a lot of money; a great handicap for rare diseases. Drugs to look out for in the future might be Tacrolimus or Rituximab. He emphasised the need for monitoring patients, ie with regular blood tests. He admitted that the monitoring was not as good as it should be, and this is where MG nurses could help.

Gold Award and Silver Award

At the conference the MGA Chairman presented the following awards.

The Silver award was presented to Mrs Vera Kilbey for the work she had done in Kent to support Myasthenics. For years she had been an officer in the Kent branch and due to her endeavours, MG patients were now benefitting from better services from the NHS in Kent.

The Gold award is not very often given except in exceptional circumstances, but the MGA Board had no hesitation in giving this award to Mrs Daphne Crook Hampshire branch. It was during the Second World War that she was diagnosed with MG. She worked for years helping with the Muscular Dystrophy Charity until the MGA was formed. She was one of the founding members of the Hampshire branch, and she is still baking cakes and helping in the branch today!

We sincerely congratulate both these ladies.

Joan Finney

A special thanks to Steve Saunders for organising this event and to branch members working in the kitchen who provided us with an excellent lunch.