

No. 180 January 2012



Teamspirit

For branch officers and national support group committee members

Welcome to the January edition of Teamspirit.

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Don't forget – the information in the first six sections is for **everyone**, wherever you are in the UK.

Get in touch

We're always keen to hear your feedback, so if you have any comments, suggestions or ideas email teamspirit@mssociety.org.uk, phone 020 8438 0741 or write to Teamspirit, MS Society, 372 Edgware Road, London NW2 6ND.

If you're a newsletter editor, email teamspirit@mssociety.org.uk to receive a version of Teamspirit that you can copy and paste into your branch or regional newsletter.

Branch donations

Branch or group	Description	Earmarked	Research	General
Angus	Edinburgh Translational Research Centre	£10,000.00		
Ayrshire			£10,000.00	
Bedford			£1,000.00	
Belfast	Day Centre and Research	£5,000.00	£5,000.00	
Bolton & District	MS Nurses	£2,000.00		
Bolton & District	Fairer Financial Assistance Fund	£2,000.00		
Brentwood & Chelmsford	Cambridge Centre for Myelin Repair	£1,000.00		
Chorley & District	Stem Cell Research	£5,000.00		
Clydebank & District			£1,000.00	
Colchester & District	Cambridge Centre for Myelin Repair	£3,000.00		
Crawley & District			£4,500.00	
Devizes, Chippenham and District			£500.00	
Fermanagh			£2,000.00	
Gillingham & Shaftesbury	Fairer Financial Assistance Fund	£500.00	£500.00	
Gosport & Fareham	Cambridge Centre for Myelin Repair	£4,000.00		
Great Yarmouth & District			£2,000.00	
Hastings & Rother	Cambridge Centre for Myelin Repair	£2,000.00		
Huddersfield & Kirklees	Tissue Bank	£2,000.00	£2,000.00	
Hull Beverley Borough & Holderness	Fairer Financial Assistance Fund	£6,000.00	£3,970.15	

continued overleaf

Branch donations

Branch or group	Description	Earmarked	Research	General
Hull Beverley Borough & Holderness	Symptom Relief Fund	£4,000.00		
Huntingdon & District	MS Nurses	£1,000.00	£1,000.00	
Inverness & Nairn			£1,000.00	
Inverurie & District	MS Register Project	£1,000.00		
Isle of Wight			£2,500.00	
Larne	Cambridge Appeal	£1,000.00		
Macclesfield			£10,000.00	
Maidenhead, Slough & District	Funding Care Navigator and MS O/T roles	£90,000.00		
Mid Cornwall	Research grant #931/10 SWIMS project	£2,500.00	£2,500.00	
Mid Ulster			£5,000.00	
Oswestry & District	MS Nurses	£1,000.00		
Oswestry & District	Cambridge Centre for Myelin Repair	£1,000.00		
Oswestry & District	Stem Cell Research	£1,000.00		
Scarborough & District	MS Nurses	£2,000.00		
Sefton Area	MS Nurses	£2,000.00	£2,000.00	
Shrewsbury & District	Cambridge Centre for Myelin Repair	£1,000.00	£2,000.00	
Skipton & Craven	Stem Cell Research	£1,500.00		
South Cornwall			£5,000.00	
South Suffolk	Stem Cell Research	£1,000.00		
South Suffolk	Fairer Financial Assistance Fund	£1,000.00		
South West Dorset			£4,000.00	
St Helens & District	Stem Cell Research	£1,000.00		

continued overleaf

Branch donations

Branch or group	Description	Earmarked	Research	General
Stirling	Edinburgh Centre for Translational Research Grant	£6,000.00		
Teesside			£2,500.00	£2,500.00
Torfaen & District				£1,000.00
Uckfield Heathfield & Lewes	MS Register Project	£2,100.00		
Wandsworth	Cambridge Centre for Myelin Repair	£2,000.00		
Warrington & District			£1,000.00	
West Oxfordshire			£2,000.00	
Worcester & District	Cambridge Centre for Myelin Repair	£3,000.00		
Worthing & District			£1,000.00	
Totals		£161,600.00	£61,970.15	£3,500.00

These are donations recorded in September and October 2011.

News and events

Get Active for MS Life & MS Week

The theme for this year's MS Life and MS Week is 'Get Active'.

'Get Active' could mean anything from doing a 10k run in aid of the Society, writing a letter to your local MP about unreasonable benefits assessments, or simply committing to 'positive thinking'. For others it could be about getting involved in volunteering for their local branch, make a donation, join a support group or sign up to the Research Network.

Get Active is about people being proactive in a way that best suits them; it's about making a positive difference to your life, or the lives of people affected by MS.

There will be plenty of opportunities for people to Get Active at MS Life (14-15 April) and for MS Week (30 April-6 May) and we'll use these and other opportunities to ask people to pledge their support. One way that branches could 'Get Active' is by hosting a Cake Break, which falls on the Friday in MS Week (4 May).

Why not consider how else your branch could adopt the 'Get Active' theme? For example, are you already planning an event around MS Week or later in 2012 that could be promoted as a 'Get Active' event?

Keep an eye on the website, where we'll be posting more information soon. In the meantime, if you want to discuss how your branch could 'Get Active' around MS Week and beyond, contact your local staff member or Jenna Litchfield or Diane Primrose in the Communications team

at msweek@mssociety.org.uk. If you are affected by MS and have attended MS Life in the past, or are attending this year, and would like to share your story to help us raise awareness of the event please get in touch with the communications team.

MS Life event information & booking details

MS Life 2012 takes place on 14-15 April at Manchester Central. Bookings are free but must be made in advance. Go to www.mssociety.org.uk/mslife to reserve your place.

Set to be the biggest event of its kind in Europe, this year's MS Life will host a range of research talks from world leading MS scientists, over 40 workshops covering everything from symptom management to benefits, an exhibition space and a 'lifestyle village' with products, services, complementary therapies and an MS spa. Fringe events include cookery demonstrations, a comedy night and a Wheel & Walk fundraiser and there's a free creche for the kids too. The full programme can be viewed on the MS Society's website.

Help us spread the word and encourage members of your branch and all those affected by MS that you can reach to attend. To request free promotional posters, postcards and booking forms, or for more general event information, email mslife@mssociety.org.uk or call 020 8438 0941.

News and events

MS Life fund

Once again the MS Society has set up a grant fund to provide financial assistance towards the cost of transport and accommodation for those attending MS Life.

Grants of up to £150 are available to people affected by MS from across the UK, with priority given to people on a low income who live a long distance from Manchester.

Grants will be awarded on a first-come, first-served basis and funds are limited – so there's no guarantee. Branches are also encouraged to offer financial support to people wishing to attend MS Life.

The closing date for applications to the MS Life fund is **30 March 2012**.

For further information on applying for a grant or to request an application form, please contact the grants team on 020 8438 0700 or by email at grants@mssociety.org.uk.

New MS pill refused again by NICE

The new pill for people with relapsing-remitting MS, called Gilenya (formerly known as fingolimod), has been refused by NICE for a second time on the grounds of poor cost effectiveness.

Gilenya was licensed by drug regulators the MHRA in April after they deemed the treatment both safe and effective. Since then, the availability of Gilenya has

depended on whether local healthcare authorities or PCTs are willing to pay for it for their patients.

In August, NICE issued draft guidance stating the treatment was not cost effective and should not be freely available to people on the NHS. A consultation followed, in which the MS Society submitted evidence and the makers of the drug reduced the price, but this announcement shows the decision from NICE remains unchanged.

A further consultation will now take place and people with MS are encouraged to submit their views. This can be found at <http://guidance.nice.org.uk/>

This will be disheartening news for people with MS and it will leave some people with no effective treatment option. The Society would like to see Gilenya freely available to all those that could benefit and remain hopeful that this will happen.

This is not a final decision, so in the upcoming consultation period the Society will again be encouraging people with MS to contact NICE with their views.

Volunteer open day

Thank you to all volunteers who attended the Volunteer Open day when the MS Society National Centre (MSNC) opened its doors to volunteers. Over 35 volunteers attended the day, with two coming from as far as Sunderland.

News and events

This was a great opportunity for volunteers and staff to get to know one another, share experiences and discuss new ways to work together to 'Beat MS'. Volunteers heard about the latest MS Society funded research and activities happening across the Society.

The Society's new Chairman Hilary Sears, due to start in January, attended the day and met and talked with volunteers.

If you attended the day and have any feedback, please contact our Volunteering Officer, Liz Wigelsworth on 020 8438 0749 or email lwigelsworth@mssociety.org.uk

Travelling safely in a wheelchair

When wheelchair users are transported by branch minibus, it is essential that a lap belt is fitted correctly to ensure the safety of everyone travelling.

A lap belt is the strap that goes over a person's waist. The purpose of a lap belt is to keep a person safe, comfortable and well positioned in the wheelchair whilst travelling.

Most wheelchairs are supplied with a factory-fitted lap belt. If a wheelchair does not have a lap belt already fitted, one can be purchased for around £4. This should be used in addition to, but never as a substitute for, an approved passenger restraint system fitted within the vehicle.

Moving into a vehicle safely

Before moving someone into a vehicle it is important that a lap belt is securely in place to prevent falls.

Once someone using a wheelchair is in the minibus, always ensure that the person and the wheelchair are safely and correctly secured in the vehicle. Note – it is important that the manufacturer's guidelines are followed, as vehicles and wheelchairs can differ significantly.

If someone is able to transfer from their wheelchair to vehicle seat easily, painlessly and without assistance they should do so, as this is generally safer and more comfortable.

Fitting a wheelchair lap belt correctly

- Ensure a correct sitting position (i.e. fully back in the seat), and that the pelvis is as upright and symmetrical as possible.
- Position the lap belt so that the hip bones can be felt above the belt.
- Adjust the length of the lap belt so that there is just sufficient room for your hand to slide between your body and the belt.
- Pass the lap belt down between the user and any side panels on the wheelchair, not over the armrests. It should fit firmly across the pelvis, not the abdomen.
- Do not allow lap belts to ride up onto the abdomen where they could cause internal injury in the event of a collision, or from which the passenger might slide out.

News and events

Fitting vehicle sash belts

- A sash belt should always remain in contact with the shoulders of the wheelchair user, lying snugly across the pelvis and fitting inside the framework of the wheelchair or seat.
- Fit the shoulder strap(s) comfortably across the collar bone (not across the throat or neck).

For more information, please contact our Branch Health and Safety Officer, Andy Grant on agrant@mssociety.org.uk or phone 07827 281 097.

Poor services for neurology despite increase in spending

A report has been published by the National Audit Office, focusing on people with multiple sclerosis (MS), motor neurone disease (MND) and Parkinson's.

The report showed that despite a £0.8 billion increase in spending for neurological services from 2006-2010, the Department of Health has no understanding of how this extra money has benefited patients.

The MS Society, along with Parkinson's UK, MND Association and the Neurological Alliance, are now urging the Government to create a targeted and properly resourced national outcomes strategy for neurological conditions. This would help to explain

what support, information and choices will be given to people with neurological conditions, set out what support the Government will provide to help neurological services deliver high quality outcomes, and show what action needs to be taken to ensure people can access high quality services. It will also ensure money is being spent appropriately while sending a clear signal that neurological services must be seen as a priority.

The report also exposed that billions of pounds have been wasted by the Department of Health through people with neurological conditions, including MS, being unnecessarily admitted to hospital.

Simon Gillespie explained – *“Every time a person is admitted to A&E because of their MS, the health and social care system has failed. When people with MS are properly supported in managing their condition, there should be no reason for unplanned admissions, which cost both patients and the NHS dearly.*

“MS specialist nurses play a critical role in providing this support and coordinating care, but with one MS nurse to every 454 people, these posts are sadly rare and many are at threat due to short-sighted budget cuts.”

We now hope to work with the Department of Health and the NHS to develop an outcomes strategy that will benefit people living with MS and other neurological conditions. We will also be giving evidence to the Public Accounts Committee (PAC) on Wednesday 18 January.

Support

Join our Calvert Trust taster weekends

Following the success of our taster activity weekends for people affected by MS last autumn, the Calvert Trust team in Kielder, Northumberland, is organising more events this year. The dates for your diary are:

- **10-13 February** – Taster weekend for young people with MS, their families, friends and carers
- **27-30 April** – MS Adventure weekend (for a longer break with half-day activities)

An adult respite care package with 24 hour care assistance is also available for both weekends.

Three nights is being offered for the price of two for the young person's weekend. The cost is £157 per person.

Three nights at the MS Adventure weekend costs £309. If care assistance is required the cost of the adventure weekend is £440.

These prices include meals, activities and fully accessible accommodation.

For more information and to make a booking, please contact the Calvert Trust on 01434 250232 or email enquiries@calvert-kielder.com. You can also visit their website at www.calvert-trust.org.uk.

Our Short Breaks and Activities (SBA) fund considers grants for people with MS and carers and may be able to contribute

towards the cost of your break. Contact the Grants team on 020 8438 0700 or email grants@mssociety.org.uk for details.

New editions from the MS Society

MS Essentials 19: Muscle spasms and stiffness (*Third Edition October 2011*)

A new edition of MS Essentials 19 on muscle stiffness and spasms is now available containing information on Sativex and how it is prescribed.

Muscle stiffness and spasms are common MS symptoms, both often described by the term 'spasticity'. Mild stiffness in the muscles can aid balance and mobility for some, but more severe stiffness or spasms can be tiring, frustration and, for some, painful. This booklet provides guidance on ways to manage these difficult symptoms.

A copy of this booklet has been sent to all branches. Please ensure you recycle all old editions of this booklet.

If you would like more copies of this title, visit our online shop at <http://shop.mssociety.org.uk> or contact our information team on infoteam@mssociety.org.uk or 020 8438 0799 (weekdays 9am-4pm).

The information team can also provide a login for bulk orders. Printed booklets are available in large print, other languages and audio versions (in selected titles).

If you do not have internet access you can telephone the order line on 0300 1000 801.

Fundraising

Thank you for your donations

Thank you to all branches and individuals who have given their support to the MS Society during 2011, particularly to those who have supported our Cambridge Centre for Myelin research appeal.

Each donation for this research will help us advance our work of understanding myelin and to develop a treatment to promote myelin repair in people with MS.

So far we have fundraised over £550,000 towards our goal of £2.1 million to fund the next stages of this research. Of this, £305,500 was kindly donated by branches.

If you would like to know more about this research visit www.mssociety.org.uk/hope

New roles to develop fundraising locally

To put the MS Society in the best possible position to 'Beat MS' in the current competitive environment, we will become more visible with the help of new Area Fundraisers who will work with branches and other community fundraisers to increase income from 2012.

Area Fundraisers will work alongside local staff and volunteers to help branches grow their income and promote more widely the Society's fundraising events and activities.

We have already trialled this role in the West Area of England with great success.

Initially we will have five Area Fundraisers in post in England, two in Scotland and one in Wales and then we'll look at other areas where help is needed, including Northern Ireland.

Area Fundraisers will not directly organise fundraising activities for branches but will help branches to:

- Assess and plan their fundraising.
- Recruit, support and develop the skills of fundraising volunteers.
- Effectively approach local community groups, charitable trusts, employers, schools and encourage joint working on events and applications between branches.
- Maximise the use of national fundraising products and activities such as Cake Break, gifts in wills and adrenalin events ie. sky diving.

Area Fundraisers will also work with and support other community fundraisers and groups not directly involved with branches.

These positions are currently being recruited and will be in place at the beginning of 2012.

If you have any further questions or would like more information then please contact:

England – Chris Bennett on cbennett@mssociety.org.uk

Scotland – Zoe Mobey on zmobey@mssociety.org.uk

Wales – Judi Rhys on jrhys@mssociety.org.uk

Fundraising

Cake Break 2012

We are encouraging you to make a difference and take part in our biggest community event of this year – Cake Break 2012. Whether you're in Scotland, Northern Ireland, England or Wales, every branch is encouraged to get involved.

This year's exuberant face of Cake Break is one of our nation's favourite chefs, Ainsley Harriott. He has entertained us for more than ten years and will now be facing his biggest test yet, Cake Break 2012.

Cake Break launches on **Friday 4 May 2012**. We would like more branches to get involved, so we will be offering branches increased support from their local area fundraisers. Please help us to raise the profile of Cake Break in your community.

From 16 January 2012 you will be able to register online at www.mssociety.org.uk/cakebreak and download your fundraising pack. Alternatively you can register by phone and receive a hard copy from our Community Fundraising team based at the MS National Centre.

If you have any queries or would like more information about Cake Break please contact Mita Vaghji, Community Fundraiser on 020 8438 0737 or email cakebreak@mssociety.org.uk.

Christmas collection commission

Our thanks to all branches that purchased gifts from the 2011 Christmas collection. Commission payments will be made by the end of March for bulk orders and orders placed using the branch media code.

Some members, who have previously purchased from the catalogue, will receive a sale catalogue in early January. The Christmas company we work with, Webb Ivory, bears all costs for these mailings. The MS Society receives commission on purchases and incurs no direct costs.

If you have any questions or feedback on the 2011 Christmas catalogue, please contact Sarah Briggs, direct marketing officer, on 020 8438 0847 or sbriggs@mssociety.org.uk

Correction: The last issue of Teamspirit wrongly stated that 30% commission was available on orders placed using a branch media code. The correct commission level is 25%.

Fundraising

'Charity of the Year' staff votes

The MS Society is in the voting stages with two companies for us to become their charity of the year – Manpower and Adecco. It's a great achievement for us to have reached this stage and now we need your help to push us over the finishing line.

If you know anyone (friend, partner, relative) who works at Manpower or Adecco, please encourage them to vote for the MS Society – every vote counts.

Why not pop in to your nearest Manpower or Adecco office and talk to the staff about the vital work that we do or if you have a relationship with them then please mention the MS Society.

For further information please contact Sue Spencer in the Corporate Partnerships Team on 0208 438 0850 or email sspencer@mssociety.org.uk

Finance

Accounts Pro forma 2011

The annual accounts pro forma pack was posted to all branch treasurers at the end of October and needs to be returned to the MSNC by 31 January 2012.

Agreed upon procedures (AUP) report

In the past larger branches have had to get an AUP report completed by an independent accountant. **For 2011 only the following branches will need to complete an AUP report:**

- Branches with shops.
- Branches with day centres.
- Branches that should have completed an AUP report in 2010 and did not do so.

Branches required to have an AUP report completed will receive a blank report in their accounts pro forma pack.

Internal Financial Controls Checklist

Internal financial controls are the checks and balances that need to be in place to ensure best use of charitable funds and to safeguard the Society's assets. The Society uses an adapted version of the Charity Commission's 'Internal Financial Controls Checklist'. You can find a version of this checklist in the Treasurers Handbook section 3.3.

For 2011 all branches whose income is £25,000 and/or reserves greater than £50,000, must complete the Internal Financial Controls Checklist and submit this to the MSNC with their accounts pro forma. It is an audit requirement.

All other branches should also complete the Internal Financial Controls Checklist and return it to the MSNC. It is good practice to go through the checklist once a year to ensure the branch has adequate financial controls in place.

If you have any queries please contact the branch finance support team at financesupport@mssociety.org.uk.

Research

New research finds rare gene linking vitamin D with MS

A study part-funded by the MS Society has identified that a gene that causes vitamin D deficiency may also cause MS. Researchers at Oxford University found a small group of people with a genetic vitamin D deficiency which has a strong connection to MS.

There is growing evidence of a link between vitamin D and MS. We get vitamin D when our skin is exposed to sunlight and also from some dietary sources. Studies have established that the closer people live to the equator the lower the risk of developing of MS, and sunlight is strongly implicated as a cause.

What's the study?

The researchers looked at people with MS who have a large number of other cases of MS in their family. When the team studied their DNA, all of the people they looked at had an unusual version of a gene called CYP27B1. Importantly gene CYP27B1 controls vitamin D levels in the body.

In a few very rare cases where people have inherited two copies of the unusual version of the gene, these people were found to have a genetic form of rickets caused by vitamin D deficiency as well as having MS. These findings suggest a strong link in these individuals between vitamin D deficiency and the development of MS.

What does it mean for people with MS?

This research offers further support to a potential role for vitamin D deficiency in MS and may also help to explain why some family's genes put them at a higher risk of developing MS.

However, there is still much to learn about the causes of MS and, if important, the role of vitamin D will only be a part of the puzzle. More work is needed before we fully understand why some people develop the condition and others don't.

This is an important development and shines more light on the potential role of vitamin D deficiency on increasing the risk of developing MS. This research is gathering momentum and will be the subject of discussion at an International Expert meeting in the USA this month. The discussion will shape future research that will give us the answers we so desperately need about the potential risks and benefit of vitamin D supplementation.

The study was published in the journal *Annals of Neurology* and was also supported by funding from The Wellcome Trust.

For England

We have protected 12 specialist posts

The hard work put in at a local level in partnership between branches, volunteers and staff at the MS Society has contributed to protecting 12 specialist nurse, physiotherapy and occupational therapy posts across the UK and ensured that people with MS have access to the specialists they need.

In 2012 it is important that we continue to actively work with decision makers locally where MS services are under threat or being reviewed and make sure we seek the best outcome for people affected by MS. If you hear of any planned changes to roles or services, please get in touch with your local Service Development Officer to discuss.

For Wales

MS Support Officer – still time to get involved

We are rolling out an exciting new support volunteer programme in 2012. This new programme aims to help branches provide a vital front line support service and to improve the range of support available to people affected by MS in your area.

The new programme includes an excellent training programme for new and existing support volunteers, as well as a new team approach to provide support.

This support team will be made up of a Lead Support Volunteer (LSV) who will co-ordinate the work of the other support volunteers and also be a committee member. The other support volunteers will have the option to sit on the branch committee if they wish to do so.

What will the role involve?

The support volunteer roles can be broken down in many different ways, here are some examples:

- You can break down the role by task, and/or by area for example, volunteers doing the entire role but in different geographical areas within the branch.
- Volunteers doing specific roles like home visits, emotional support and grants covering full branch area.

There will be a four day training programme spread across 2-4 months which volunteers will be asked to make a commitment to attend. No one will be asked to take on more work than they feel comfortable with.

The new MS Support team roles and the training provided should prove an asset to people looking for a challenge and who would like to 'make a difference', with the added benefit of learning new skills that may benefit future employment opportunities.

If you would like to take on a new challenge to be a volunteer and help support people living with MS, then please contact Sue Jones on sjones@mssociety.org.uk for more information. We anticipate that we will hold interviews during March/April 2012.

Thank you for helping save MS nurse posts

We would like to thank every branch that has so far got involved in our campaign to save MS nurse posts in Wales.

We have collected over 1,500 petitions calling on the Welsh Government to protect these posts and on 9 November we submitted the first batch of petitions to the National Assembly for Wales' petitions committee.

For Wales

If you haven't already done so, please get as many of your friends and family as you can to sign our petition. Some branches have been encouraging people to sign at information events and MS clinics, while other people have been encouraging their neighbours and local businesses to get involved.

If we can reach 2,000 signatures, we will be able to show the Welsh Government the MS nurses provide a vital service and that people living with MS are passionate about seeing them protected.

You can download a petition at www.mssociety.org.uk/get-involved/campaigns/wales or if you ring 029 2078 6676 we can send some out to you.

Using the Blue Badge Scheme in Wales

Following a number of enquiries from branches about parking charges and the blue badge scheme, we are pleased to inform you that the Welsh Government is planning to make the scheme free to badge holders giving people with MS more parking options early in 2012.

The scheme is designed to provide free on-street parking, so that people living with MS can park on single and double yellow lines for up to three hours and in specially marked disabled parking spaces.

This does not guarantee free parking in off-street car parks which are council-run or privately owned. If you use one of these car parks, please check the signage very carefully as we are aware of a number of privately-owned car parks that have recently changed their policy for disabled parking.

Please note that councils will charge up to £10.00 for organisational badges or if you lose your badge.

If you do have to pay then the pay and display machines should be accessible. If they are not, please contact Joseph Carter on 029 2078 6676 and we will campaign on the issue.

For Scotland

MS Society appoints Support Volunteer Training Officer

We are rolling out an exciting new support volunteer programme in 2012. This new programme aims to help branches provide a vital front line support service and to improve the range of support available to people affected by MS in your area.

We are pleased to announce that we have appointed Sherilyn Turkington to the position of Support Volunteer Training Officer. Sherilyn will work closely with other members of staff to deliver the new four day support volunteer training programme in Scotland, Northern Ireland, North of England and the West Midlands.

We expect that training will commence in spring 2012. More details will be available soon, but if you have any questions please contact Volunteer Development Manager Lynda Boyce on 0131 335 4050 or email lboyce@mssociety.org.uk

On the political agenda: better care for people with MS

We held a reception at the Scottish Government during December 2011 on **better care for people with MS**. MS Society members and staff met with MSPs to discuss how people with MS in Scotland still face a postcode lottery when it comes to accessing neurological services.

Rhoda Grant MSP also hosted a debate in parliament on the provision of **better care for people living with MS**. As part of the debate MSPs discussed the *Clinical Standards for Neurological Services*, the contribution of MS specialists and specialist training for professionals.

NHS Quality Improvement Scotland will begin an assessment of how health boards are implementing the *Clinical Standards for Neurological Services* this month. Scotland's Service Development Manager, Andrew Johnston will participate in this evaluation.

If you and other members of your branch are keen to be kept up to date on policy issues why not join our policy forum? Members meet four times a year and receive a monthly e-newsletter on the latest campaigns.

For more details, please contact Policy Officer Jo O'Neill on 0131 335 4050 or email joneill@mssociety.org.uk

For Scotland

ms space Lanarkshire

ms space, a regional event held in Lanarkshire on 30 September, was a huge success and gave people affected by MS in Scotland an opportunity to find out information about MS, try new therapies, find out about local services and meet new people.

The most highly rated session of the day was a talk by Professor Charles ffrench-Constant, Co-director of the Centre for Translational Research, who spoke about the latest MS Society funded research that has shown that it is possible to repair damaged myelin, the cause of MS.

Delegates had the chance to enjoy group sessions on self-management, exercise and relaxation techniques and the opportunity to meet local specialist nurses and a physiotherapist.

The Society's Strategic Lead for Carers, Sue Allison gave an overview of our strategy to support carers, which will launch in Carers Week 2012.

To talk more about improving access to short breaks for people affected by MS, Ben Hall from Shared Care Scotland and Julie Gilson from the MS Society ran a session. This focussed on the Short Breaks and Activities Fund that the Society launched in early 2011 and how people with MS can get the most out of it.

Welfare reform was also on the agenda with Citizens Advice Scotland and MS Society policy staff discussing the major changes to Disability Living Allowance (DLA) and Employment and Support Allowance (ESA).

Delegates were also informed about new Support Volunteer roles which are being rolled out across the UK.

Thank you to everyone who attended and made the day a success.

For more information about the day, please contact Marion MacNeil, Information Manager, on 0131 335 4050 or email mmacneil@mssociety.org.uk.

Branch raffles, prize draws and collections

All raffles, prize draws and collections are subject to strict legislation so we are here to guide you through the forms that need to be completed.

If your branch has held or will be holding a raffle in 2011, please contact Fiona Harvey in the fundraising team on 0131 335 4065 or email fharvey@mssociety.org.uk

For Scotland

Scottish Medicines Consortium assess Gilenya

The Scottish Medicines Consortium is currently assessing Gilenya (formerly known as Fingolimod), the new pill for relapsing remitting MS.

Gilenya was licensed by drug regulators MHRA in April 2011 after they deemed it both safe and effective. However, the treatment must be assessed by the Scottish Medicines Consortium before it can be routinely prescribed by health boards in Scotland.

Last year in England, Gilenya was refused by NICE on the grounds that it was not cost-effective.

We would like to see Gilenya freely available to all those who could benefit and we have submitted our views to the Scottish Medicines Consortium.

A decision on Gilenya by the Scottish Medicines Consortium is expected in March 2012.

For Northern Ireland

New support volunteer programme

We are rolling out an exciting new support volunteer programme in 2012. This new programme aims to help branches provide a vital front line support service and to improve the range of support available to people affected by MS in your area.

The new programme includes an excellent training programme for new and existing support volunteers, as well as a new team approach to provide support.

This support team will be made up of a Lead Support Volunteer (LSV) who will coordinate the work of the other support volunteers and also be a committee member. The other support volunteers will have the option to sit on the branch committee if they wish to do so.

The support volunteer roles can be broken down in many different ways. Here are some examples:

- You can break down the role by task, and/or by area for example, volunteers doing the entire role but in different geographical areas within the branch.
- Volunteers doing specific roles like home visits, emotional support and grants covering full branch area.

Several engagement events have been held to inform branches in Northern Ireland about this new programme.

Each branch has been asked to fill in a self assessment form to help the committee decide how many support volunteers the branch requires and how the roles will be allocated. The deadline for returning the self assessment to your Area Development Officer is 20 January 2012.

The development team, made up of the Northern Ireland regional development manager and area development officers will be leading and co-ordinating the recruitment of volunteers centrally. There will be an advertisement in the Belfast Telegraph, Newsletter and Irish News in January 2012. We will also be advertising with Volunteer Now and through local volunteer centres.

Each committee will select a branch representative (branch chair where possible) to be involved in the volunteer recruitment process which will take place from 20 February - 5 March 2012.

Each committee representative will have the opportunity to interview potential volunteers, along with their Area Development Officer, to assess their suitability for the role.

Once potential volunteers have been recruited into the role, they will take part in a four day training programme. Training will take place from March to June 2012 in various locations throughout Northern Ireland.

For Northern Ireland

Branch forum

A branch forum will be held in Belfast for branches to come together to share ideas, experiences and best practice. Guidance will be given to committees to prepare for branch annual meetings.

It is important that each branch is represented, so please encourage your committee members to attend.

The event will be held at the MS Society NI Resource Centre, 34 Annadale Avenue, Belfast BT7 3JJ on 18 January from 11.00am to 2.00pm.

Please confirm your attendance with your Area Development Officer.

Fundraising workshops

Fundraising workshops will be held in 2012 to look at ways to maximise income from community based events and activities and also to ensure we are making best use of local fundraising contacts and opportunities.

Further details will be announced early in 2012.

Corporate contacts

We are currently looking for opportunities to be nominated as the 'charity of the year' by local businesses. Do you or someone you know work for a company who runs a scheme like this? If so please contact our fundraising team on the number below.

We are keen to work with branches and our supporters to maximise partnership opportunities at a local level, support and income. The Mid Ulster branch recently partnered with the 'Mid Ulster Truckers' and will be working throughout 2012 raise awareness and funds in the Mid Ulster area.

If you would like to discuss a potential opportunity, please call Tom Mallon on 028 9080 2802.

Classifieds

Please share these opportunities with people with MS and carers in your area.

Lisnaskea

MS Society Northern Ireland has two fully accessible chalets available for hire at the SHARE village in Lisnaskea. The cost is £150 per week and includes a SHARE fitness leisure pass. Bookings are taken on a first come, first served basis. To book a holiday please contact Mark on 028 9080 2802 or mhatte@mssociety.org.uk.

Amberwood Holiday Lodge

West Herts Branch has a holiday lodge at Shorefield Holiday Village, near Lymington, Hampshire, for people with MS, families and carers. The chalet has a master bedroom with en suite shower room, a twin bedded room, bathroom, and lounge/ kitchen area with double fold-out sofa bed. An electric wheelchair and scooter are provided. Further details from Ken Gordon on 01442 243023 or by email ken@subcondrilling.co.uk.

Arjo Sara Plus Hoist

An Arjo Sara Plus hoist, which can be used for both rehabilitation and maintenance therapy by helping a person rise, stand and be used as a walking aid, is free to a good home. This device is only three months old and in excellent condition.

To be able to use this hoist, the person affected by MS would need to contact their Occupational Therapist or medical specialist to find out if this device was suitable for them.

Please note, if interested you would need to renew the service contract with the supplier Arjo.

For more information please contact Adam Willis on 01933 356079. You will need to be able to collect the hoist from Northamptonshire.

Mention of advertisement by the MS Society of products or services is not an endorsement by the MS Society, its volunteers or staff.

Teamspirit directory

MS Society

MS National Centre
372 Edgware Road
London
NW2 6ND
020 8438 0700

MS Society Cymru

Temple Court
Cathedral Road
Cardiff
CF11 9HA
02920 786 676

MS Society

Northern Ireland

The Resource Centre
34 Annadale Avenue
Belfast
BT7 3JJ
02890 802 802

MS Society Scotland

National Office
Ratho Park
88 Glasgow Road
Ratho Station
Newbridge
EH28 8PP
0131 335 4050

Support groups

There are support group for Jewish people, lesbians and gay men, Afro-Caribbean people, Asian people, and former and serving members of the armed forces.
020 8438 0856
susmani@mssociety.org.uk

Find us online

www.mssociety.org.uk

www.facebook.com/mssociety

www.twitter.com/mssocietyuk

www.youngms.org.uk

www.facebook.com/childrenwithMS

Grants

020 8438 0700
grants@mssociety.org.uk
(England, Wales, Northern Ireland)
0131 335 4081
grantsscotland@mssociety.org.uk
(Scotland)

National MS Helpline

0808 800 8000

MS Information Line

020 8438 0799

Membership

020 8438 0759

Volunteering

020 8438 0944

Fundraising

0870 241 3565

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372 Edgware Road
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