

No. 186 January 2013



# 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](mailto:teamspirit@mssociety.org.uk), phone 020 8438 0825 or write to Teamspirit, MS Society, 372 Edgware Road, London NW2 6ND.

If you're a newsletter editor, email [teamspirit@mssociety.org.uk](mailto: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	Institute of Child Health, Birmingham Children's Hospital	£5,000.00		
Angus	Edinburgh Centre for Translational Research Grant	£5,000.00		
Ayrshire			£15,000.00	
Bedford	Cambridge Myelin Repair 2011-2015	£1,692.00		
Bedford	Cambridge Myelin Repair 2011-2015	£3,000.00		
Berwick & Eastern Borders	MS Nurses	£1,500.00	£1,500.00	
Bolton & District	MS Nurses	£2,000.00	£2,000.00	
Brentwood & Chelmsford	Cambridge Myelin Repair 2011-2015	£1,000.00		
Burton On Trent	Cambridge Myelin Repair 2011-2015	£3,000.00		
Chorley & District	Cambridge Myelin Repair 2011-2015	£1,000.00		
Colchester & District	Cambridge Myelin Repair 2011-2015	£3,000.00		
Colchester & District	MS Nurses	£3,000.00		
Crawley & District			£9,000.00	
Darlington & District			£1,000.00	
Hull Beverley Borough & Holderness	Cambridge Myelin Repair 2011-2015	£2,500.00		
Hull Beverley Borough & Holderness	Amiloride Clinical Trial in Optic Neuritis (grant 952)	£2,500.00		
Inverness & Nairn			£2,000.00	
Isle of Wight			£2,000.00	
Mid Cornwall			£1,000.00	
North Devon			£2,000.00	

# Branch donations

Branch or group	Description	Earmarked	Research	General
North Dorset & District				£2,000.00
Oldham & District	Stem Cell Research	£2,000.00		
Orkney	Edinburgh Centre for Translational Research Grant	£3,000.00		
Orkney	Cambridge Myelin Repair 2011-2015	£3,000.00		
Oswestry & District	Stem Cell Research	£500.00		
Oswestry & District	MS Nurses	£500.00		
Oswestry & District	Cambridge Myelin Repair 2011-2015	£500.00		
Ross-Shire				£2,500.00
Settle, Bentham & District			£1,000.00	
Shetland Branch			£5,000.00	
Shrewsbury & District			£4,515.24	
Stratford Upon Avon & District	Cambridge Myelin Repair 2011-2015	£1,000.00		
Teesside			£3,000.00	£3,000.00
Telford & District				£500.00
Wandsworth	Short Breaks and Activities	£47,461.30	£2,000.00	
Warrington & District			£1,000.00	
West Oxfordshire	Cambridge Myelin Repair 2011-2015	£2,000.00		
Worthing & District			£1,500.00	
<b>Total</b>		<b>£94,153.30</b>	<b>£53,515.24</b>	<b>£8,000.00</b>

These are donations recorded 15 September to 14 November 2012.

# News and events

## Chief Executive's post-Board report (6 December 2012)

Welcome to this update on key aspects from the work of the MS Society's Board of Trustees following its meeting on 6 December 2012. This meeting took place at MS National Centre in London. The full Board papers are available on the MS Society's website at <http://www.mssociety.org.uk/ms-resources/board-meeting-agenda-december-2012>

### Regular reports

Key features in the Chief Executive's update to the Board and the latest management accounts were:

- The MS Society has been working with the Department of Work and Pensions and a number of other organisations to improve the assessment for Employment and Support Allowance; important changes to the application form have been secured, which will take into consideration the impact of fluctuating conditions such as MS
- Seven 'Living with MS' events were held between September and December 2012; these events included discussion on topics such as the latest research updates, symptom management and employment
- There was a significant level of media coverage of the MS Society Awards and the MS Society's role in supporting the Hardest Hit campaign, which highlights the impact which cuts will have on disabled people

- The financial health of the MS Society was reported to be generally good, with a lower than budgeted deficit reported at the end of the third quarter of 2012

### National Councils 2012 reviews and 2013 annual plans

The Board discussed the achievements of the National Councils in 2012; the National Councils' annual plans for 2013 were approved by the Board.

### Annual Plan and Budget

The Board were provided with the draft plan for 2013 to 2015, and the budget for 2013. A discussion was held and the Board approved the annual plan and budget.

### Next Board meeting

The next meeting of the Board will be held at MS National Centre on Thursday 21 March 2013. If you would like to attend as an observer please contact Rebecca Hawkins, Chief Executive's Office Administrator, at [governance@mssociety.org.uk](mailto:governance@mssociety.org.uk) or 020 8438 0700. The key issues for discussion at this meeting are likely to include:

- Updates from Committees of the Board
- Discussion on the vision for the Society's future work

If you have any comments or questions please contact me at [sgillespie@mssociety.org.uk](mailto:sgillespie@mssociety.org.uk) or write to me at MS National Centre, 372 Edgware Road, London NW2 6ND.

# News and events

As you may have heard, I will be leaving the MS Society in February 2013 to take up the role of Chief Executive of the British Heart Foundation. I am sad to be going and I would like to thank you all for your support for me over the last six and half years.

Patricia Gordon, Director of MS Society Northern Ireland, has been appointed as Acting Chief Executive while recruitment begins for a permanent replacement. We will update you in due course what this means for Patricia's duties in Northern Ireland in the interim. You may be aware that Patricia has also been acting as Director of MS Society Scotland. Patricia's role in Scotland will cease when Christine Carlin, our new Director of MS Society Scotland, takes up her post on January 21.

Thank you for your work and support of our efforts to provide the best outcomes for people affected by MS.

Yours sincerely,



**Simon Gillespie**  
*Chief Executive*  
December 2012

## MS Society priorities across 2013

2013 is set to be an important year for us at the MS Society, not just because we are celebrating our 60th anniversary, but also

because it is an exciting time of change. It is a year for us to reflect on how far we have come, but also to prepare ourselves for the future – a future where people with MS are able to live their lives to the full.

To do this, in early 2013, we will be engaging with our volunteers and others in the MS community to refresh our long-term vision, and set a direction of travel for the next 20 years. We'll be looking for new ways to significantly increase our income, so we can continue to fund vital research.

We will also be exploring how our volunteers and staff can work locally to achieve the greatest impact. See the article on page 7 for more information on this project.

In addition, we'll be sure to introduce a little "60th sparkle" to our anniversary year. But, we will need your help with this. From gathering stories from across the MS community, to our anniversary packs, see the story on page 5 to see how you can get involved with our 60th celebrations.

## 60th anniversary update

This year is 60 years since Mary and Richard Cave founded the MS Society to support and empower people affected by MS. There's lots happening to mark the occasion – here's how to get involved.

### Use the anniversary logo

We have a special logo that can be used on MS Society materials from 1 January to 31 December 2013.

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You can use this logo on materials that won't last past the end of 2013. For example, you can put the 60th logo on an event poster in June 2013, because the poster will no longer be used in 2014. But, on a booklet about a branch or service use the main MS Society logo as it may be in use after 2013.

## Tell your story

We are collecting and sharing the stories and photos of people affected by MS, as well as the history of the MS Society as a whole. We already have some collected, and we will shortly make them available for you to use.

The types of stories we're collecting include:

- How life has changed since 1953
- Memories of the MS Society
- Memories of your branch
- Hopes for the future for MS and the MS Society

## Add "anniversary sparkle" to your activities

This month branches and support groups will receive a one-off birthday pack of promotional materials to help you raise awareness and funds.

MS Week, nation council meetings, national fundraising events, the AGM, MS Frontiers and the MS Awards will be marking 60 years by sharing the history of the MS Society and the stories of people affected by MS. We will also hold a special anniversary lecture on 2 December 2013.

For more information about the 60th anniversary see the volunteer microsite

at [www.volunteers.mssociety.org.uk](http://www.volunteers.mssociety.org.uk) or email Sally Wrench at [60years@mssociety.org.uk](mailto:60years@mssociety.org.uk).

## UK Volunteer Opinion Survey 2013

### Have your say

In previous editions of Teamspirit we told you about plans to run a UK wide volunteer opinion survey in 2013. The survey is now live and you have until **1 February to respond**.

The survey is your chance to share your experience of volunteering with us and make sure your views are heard. What you say will help us better support all our volunteers and make important decisions about how we develop volunteering at the Society.

We want to hear from as many volunteers as possible so please encourage your branch or group to complete the survey. We want to hear from everyone – it doesn't matter how long they have volunteered with us or what their role is.

The results of the survey will be published in the summer alongside our conclusions and an action plan.

You should have received a copy of the survey by email or post during the first week of January. If you haven't yet received a copy, need some more copies for your branch or group or have any other questions, please contact Petula Storey on 020 8438 0944 or email

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[volunteering@mssociety.org.uk](mailto:volunteering@mssociety.org.uk).

You can also complete the survey online at <https://www.surveymonkey.com/s/volunteersurvey2013>.

## Working Locally

On page 5, you may have read about the MS Society's main priorities across 2013. One of these is Working Locally – a two year programme of work looking at how the MS Society operates on a local level, and how it meets the current needs of people with and affected by MS.

The work will develop an updated understanding of what people with and affected by MS need locally, as well as what the Society currently offers locally across the UK. In addition it will explore whether we should aim to be more consistent in what we offer locally, how we would achieve that, what the implications are, and how we can be more flexible locally to ensure that needs are met.

Throughout the year, you will have opportunities to share your views on these issues. Keep an eye on the volunteer microsite and future editions of Teamspirit, to find out how you can get involved and share your views.

If you have any questions, contact your local area staff member.

## Local support groups

At the 2011 AGM, a resolution was put forward about our approach to new support groups. The resolution stated that the

Board of Trustees should actively assist the growth of new support groups in our local structures, allowing them to be independent and fully supported, without undermining our existing branch structure.

Since then, we have carried out work to respond to the resolution. We have now completed this, and can confirm that the majority of our support groups (such as male carers groups, after work groups etc) are linked to branches as part of their local activities.

In addition to these branch support groups, there are a number of support groups across the UK which are not linked to a local branch. These groups are not designed to meet all the expectations of a branch. However, to ensure that we can still fully support these groups (and that they are able to use our charity number and brand) there is now a set of criteria that such groups must meet.

These groups must:

- have their own bank account within cash pooling
- have two named 'lead volunteers'

The creation of these types of support groups has not been common in recent years. Where any potential new support group arises, local staff will first explore the option of linking the support group to a local branch. Many branches continue to develop thriving support groups as part of their normal range of activities and this is likely to be the most common approach going forward.

We will be developing a "how to guide" that explains and clarifies roles, responsibilities and legal requirements for support groups, both attached to and separate from

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branches. This will be available on the volunteer microsite, and more information will be in a future Teamspirit. You can also contact your local area staff member for more information.

## Information Management Programme

With a range of important projects taking place in 2013, there is a real need to improve the way we capture, store and share information across the Society. The Information Management Programme (IMP) is a collection of projects that will help us do this, gathering resources to support staff and volunteers in their work. The programme will also enable us to use our knowledge to manage risks, make better decisions and ultimately improve the service and information we provide for people affected by MS.

### MS Portal

One of the programme's key projects is the MS Portal which will provide an internet-based platform for staff and volunteers to access and upload a variety of information. This will deliver a range of benefits to branches such as:

- enabling easy access to essential data such as membership lists
- simplifying and streamlining the way branches share knowledge with each other and with the national centres
- providing quick access to MS Society news, events calendars and resources

- helping branches use the skills and time offered by volunteers more effectively
- allowing branches and volunteers to maintain their own information on a dedicated database

We will soon be contacting volunteers across the UK to understand what your needs would be from such a system and will be providing ways for everyone to submit feedback. We are also looking for a number of people to become key contributors, working with us to develop a fuller understanding of the tools that would be useful for branches and volunteers. If you're interested in getting involved email Gethin James at [imp@mssociety.org.uk](mailto:imp@mssociety.org.uk).

## A review of our magazines

Some of you may be aware that, in 2011 and 2012, we reviewed the magazines we send to our members, supporters and other key audiences.

The review was generally very positive, and members said they particularly liked receiving MS Matters: it is trusted, well-read and passed on to others. A number of areas were identified for improvements, some of which we have already taken forward, such as including more research content in MS Matters.

One of the findings of the review was that members in Scotland, Wales and Northern Ireland value receiving nation-specific news, features and personal stories, but they also place a premium on our magazines being produced cost effectively. Of members



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surveyed in Scotland, Wales and Northern Ireland, 48 per cent said they would be happy to receive just one magazine, as long as they continued to receive nation-specific content (only 15 per cent disagreed, with the rest expressing no view either way).

## A new-look MS Matters

Taking these findings into consideration, we recently decided to combine MS Matters with our nation magazines. In the summer of 2013, we will launch a new-look MS Matters which will differ according to the country in which the recipient lives. Magazines sent to Scotland, Wales and Northern Ireland will feature four-eight pages of nation-specific content at the front, and will also feature stories from across the UK throughout. This means we will stop producing MS Connect, MS Linc and the NI Newsletter, the last issues of which will be in the spring.

We believe this change will have several benefits:

- we will increase the frequency of nation-specific news reaching our members
- activity happening in the nations will reach a larger audience
- we will stop duplicating content between magazines
- we will save around £40,000 by producing and distributing just one magazine across the UK

At this stage, we do not plan to make significant changes to the version of MS Matters received in England, as our survey showed extremely high satisfaction with MS Matters among members in England, with no evidence of demand for

additional content that is England-specific (most of the content in MS Matters is already highly relevant to members in England). However, we will keep this under review.

## New editions of MS Society publications

### **Benefits and MS (MS Essentials 09)**

*Eighth edition, October 2012*

### **Claiming DLA (MS Essentials 13)**

*Ninth edition, October 2012*

*Please recycle all old editions of these guides.*

Sample copies of both booklets were sent to all MS Society local branches in November.

If you would like copies of these titles, visit our online shop at <http://shop.mssociety.org.uk>.

If you need a login for bulk orders please contact the information team at [infoteam@mssociety.org.uk](mailto:infoteam@mssociety.org.uk) or call 020 8438 0799 (weekdays 9am-4pm).

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

### **Hearing factsheet**

*Second edition October 2012*

Although not a common symptom, hearing problems can sometimes be caused by MS. They might, for example, come on during a relapse and improve once the relapse is over. But some people do experience longer lasting changes to their hearing. This is available for download only.

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## Key publications list

For a list of all our key publications showing the latest editions and revisions visit the website: [www.mssociety.org.uk/resources](http://www.mssociety.org.uk/resources) (or search on the phrase 'key publications').

## Feedback on publications

Can you spare five minutes to help us improve our information booklets?

We're encouraging anyone who reads our booklets to give us their feedback. Whether they are people with MS, family, friends or people with no direct connection to MS, if they've read the information, we'd like to know what they think.

The short survey is online at <https://www.surveymonkey.com/s/RMH9PGJ> and will only take five minutes to complete. Alternatively, we can go through it on the phone – call the information team on 020 8438 0799.

## MS Week and Cake Break 2013

In MS Week 2012, we raised awareness of MS by producing a report called 'Fighting Back', which led to significant media coverage, including BBC Breakfast and ITV's Daybreak, as well as a number of national and regional newspapers. We also produced three videos that were watched over 30,000 times – making them among the most viewed not-for-profit videos on

YouTube that week. The campaign helped us show some of the everyday issues people with MS face, and brought public perceptions about the condition into the spotlight. We also raised over £300,000 from Cake Break, which fell on the Friday of MS Week.

In 2013, our focus will be on fighting for improvements in MS services, across the UK. Thanks to the 'My MS, My Needs' survey, sent to all adult members with MS in October, we will be able to produce detailed reports showing variation in access to MS treatments and care in a way we have never been able to do before.

Many thousands of completed surveys have now been received and we will be busy analysing the results in January and February, so we don't yet know exactly which areas of inequality our campaign will focus on – but we do expect the results to show significant variation across the UK.

Once we have the results, we'll share them with you so that you can be armed with the information and tools you need to campaign for change in your communities and get the message to your local politicians and decision-makers.

## Cake Break

In the meantime, Cake Break remains a key part of MS Week and we're aiming to raise even more money in our 60th anniversary year. With your help we hope to raise £350,000 to support the MS Society's work both locally and nationally. Your branch should already have been contacted to see if you want to receive a personalised

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Cake Break pack, and all branches which requested one should receive it next week. The branch Cake Break pack will include all the tools you need to start promoting Cake Break in your area and to encourage people to sign up.

If you haven't requested a pack and would like to get involved, it's not too late. Please contact your area fundraiser, email [cakebreak@mssociety.org.uk](mailto:cakebreak@mssociety.org.uk) or phone 0845 481 1577. Supporters interested in hosting a Cake Break can register to receive a free fundraising pack at [www.mssociety.org.uk/cakebreak](http://www.mssociety.org.uk/cakebreak).

## Are you in contact with your MP?

MPs are always asking us for real stories – they want to know about the lives of their constituents and how changes they make in Parliament are impacting on people.

This is why it makes a real difference when MS Society branches build relationships with local MPs. By hearing about the lives of people affected by MS, they can make the case for policies that will have a positive impact for our members.

For example, the Policy and Campaigns team recently worked with the Hambleton and Richmondshire branch to support their local event during the Hardest Hit campaign week of action. They invited James Wharton, the Conservative MP for Stockton South, to join a panel of local experts for a Question Time style event.

Melva Steckles, Hambleton and Richmondshire branch volunteer, said: “Engaging with a cross section of local experts and an MP was a challenge but the results were really pleasing and surprising. Our attendees got full and honest answers... Our MP said he had learnt a lot about MS and the needs of those with MS, carers and MS professionals.”

On a national level we work with a group of parliamentary supporters who are committed to tackling MS issues – the All-Party Parliamentary Group for Multiple Sclerosis (APPG). We want to ensure our work nationally is properly joined up with what is happening locally and reflects the everyday challenges of people living with MS.

### Getting in touch with your MP

If you're thinking about engaging with your MP, take a look at the 'Involving your MP' guide in the local campaigning toolkit – <http://volunteers.mssociety.org.uk/resources/107>

If your branch is already in contact with local MPs, whether positive or negative, frequent or just a one off, please let us know. You can contact Samantha Kennedy at [campaigns@mssociety.org.uk](mailto:campaigns@mssociety.org.uk) or on 020 8438 0700.

# Research

## Help set the MS Society's research priorities

Do you have an unanswered question about the prevention, diagnosis, prognosis or treatment of MS?

The MS Society is leading a new project to put people affected by MS at the centre of setting research priorities. We hope to find the top 10 unanswered questions in MS research, which will become research priorities for the Society and hopefully other funding bodies too.

For this project to be successful we need as broad a range of questions as possible to be submitted. If you have MS, are affected by MS, care for someone with MS or are an MS professional – we want to hear from you. We would like you to use your own experiences to share the questions that are most important to you.

You can share your questions through our survey – you will find a link to the survey on our website at [www.mssociety.org.uk/JLA](http://www.mssociety.org.uk/JLA). It should only take a few minutes to complete and you can submit more than one question. The survey will remain open until the end of January 2013. If you would like to receive a hard copy of the survey, please contact Mital Patel on 0208 438 0708 or [MPatel@mssociety.org.uk](mailto:MPatel@mssociety.org.uk).

If you contribute to the survey, in March 2013 you'll be able to vote for the questions most important to you. In April 2013, a small workshop will be held to discuss the questions and find the top 10 unanswered questions in MS research.

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## MS Register: Have **YOU** registered yet?

Almost 10,000 people have now signed up to the UK MS Register – that's about one in 10 of all people with MS in the UK. But we need more people with MS to sign up if the MS Register is to have most impact and achieve its full potential.

Findings from the MS Register were published towards the end of 2012. This first glimpse tells us that around half of people on the MS Register experience anxiety or depression. Depression was higher in progressive forms of MS, whereas anxiety was higher in relapsing-remitting MS.

Results also showed that the number of people with MS who are in employment is much lower than the general population. Up to four years after diagnosis only 42 per cent of people remained in employment.

These results show the unmet emotional needs of people with MS and the number of people with MS who are not working. We know that with the right support people who wish to remain in work could do so for much longer. We also know that psychological treatments, such as cognitive behavioural therapy (CBT) can really help people with MS and should be considered in health care planning.

This is exactly why we need this data – to campaign for more support for people with MS. So please join the MS Register today and help us beat MS.

# Research

Registering is very simple – just log on to [www.ukmsregister.org](http://www.ukmsregister.org) and submit details about your MS and how it impacts on your life. You must live in the UK and have an email address. The website explains in more detail how the Register will work.

## Progressive MS announcements coming up

2013 is shaping up to be an eventful year for progressive MS research.

Early in 2013 we are hoping to announce funding of a groundbreaking clinical trial for progressive MS. Details of the trial are still being confirmed but it will be the first of its kind in progressive MS.

In 2012 we announced that we were leading an international progressive MS collaborative to speed up development of treatments for progressive MS.

We have been working behind the scenes with MS societies in the USA, Italy, Canada, Netherlands and the MS International Foundation to establish research priorities that will help to reach this goal. We are hoping to make announcements on the progress of this unique collaboration in the first half of 2013.

Look out for announcements on both of these projects in the new year, on our website and in future issues of Teamspirit.

# Support

## MS activity weekend at Calvert Trust Kielder

In May 2013, the Calvert Trust centre in Kielder, Northumberland, will be hosting another dedicated activity weekend for people with MS, their families and friends. Over the weekend guests can try taster sessions of fully accessible activities such as sailing, climbing and archery, relax in the games room or hydrotherapy pool or enjoy the beautiful surroundings of the Kielder Water and Forest Park.

Fully accessible accommodation is available in the centre or self-catering Scandinavian-style lodges. Three night's accommodation, activities and meals cost £317 per person, or guests can stay on the respite care package for £488.

The MS activity weekend will take place from Friday 24 to Monday 27 May 2013. To make a booking, call the Calvert Trust Kielder team on 01434 250 232 or email [enquiries@calvert-kielder.com](mailto:enquiries@calvert-kielder.com).

## Carers Week 2013

The results are in: and the figures show Carers Week 2012 was a success nationally, as well as for the MS Society as a partner. We've signed up alongside seven national charities including Carers UK, Carers Trust, Age UK and Parkinsons UK to celebrate the contribution made by the UK's six million carers, and raise awareness of the issues they face.

Carers Week will return on 10 June 2013, so get the date in your diary now! There will be regular updates in Teamspirit to keep you up to date with what's happening nationally, so you can think about how to get involved locally.

To give you an idea of what we need to do to make Carers Week 2013 bigger and better than 2012, here are just a few examples of what we achieved this year:

- 1,900 local events registered across the UK, with 64 event packs requested by people with an interest in MS
- MS Society branches organised workshops, awareness talks and events
- Carers Week was trending on Twitter – meaning it was the most tweeted subject at that time
- Carers of people with MS engaged 29 influential MPs at a reception in Westminster

If you have any thoughts, ideas or suggestions for Carers Week 2013, we'd love to hear from you. Contact Natalie Pink on [npink@mssociety.org.uk](mailto:npink@mssociety.org.uk) or 020 8438 0805.

# Support

## Supported short breaks still available

People with MS and their families can still access care and support during a short break or holiday, through our partnership with Carers Trust and local Crossroads Care schemes.

The supported short breaks service means that family carers can get support with caring at their holiday destination, and enjoy a real chance to rest and recharge their batteries. Trained carer support workers provided by Crossroads Care will come to the holiday accommodation to help with caring at the times help is needed.

Idris Gwilt and his wife used the service during a weekend break in Aberaeron, a small coastal town in Wales. Idris uses an electric wheelchair and has support from paid carers in the morning and evening. The couple found an accessible Bed & Breakfast in the town, and arranged for Crossroads Care Mid & West Wales to visit their accommodation each morning for an hour, to provide support when they wanted it.

Supported short breaks are currently being piloted for people with MS living in England and Wales. Breaks in most areas of Wales, the south coast of England or East Anglia will be supported.

To find out more about the service, including terms and conditions, pricing, how it works and how to book, call Natalie Pink on 020 8438 0805 or email [shortbreaks@mssociety.org.uk](mailto:shortbreaks@mssociety.org.uk).

# Fundraising

## MS Society Branches Tesco Collections

As you may know, Tescos across the country regularly hold in-store collections for both local and national charities. We recently sent out letters and application forms to all of our branches to apply for a slot in this scheme. The applications for January-July 2013 have now been processed, and letters and emails confirming whether or not your branch's application has been successful have been sent out.

The applications for July-November 2013 will be sent to Tesco on your behalf this month. We will keep you informed about the outcomes of these applications later in the year.

If you have any questions about the Tesco Collection scheme, please contact Zoe Walker at [Tesco@mssociety.org.uk](mailto:Tesco@mssociety.org.uk) or 020 8438 0752.

## Challenge60

In spring 2013, we will be launching Challenge60; an innovative fundraising drive to celebrate and build on all the achievements we've made together in the last 60 years. Supporters will be asked to help raise £250,000 in 60 days for research, with the countdown starting on Friday 31 May.

The fundraising team are already gearing up to make Challenge60 the biggest and best fundraiser of the year. We'd love you and your supporters to join us in jumping out of planes, taking on a sponsored silence, dying our hair orange, doing the three peaks challenge and so much more.

If you would like to take part in Challenge60 please email [fundraising@mssociety.org.uk](mailto:fundraising@mssociety.org.uk) and we will contact you when we launch.



# Finance

## Donations sent to national offices

You may not be aware but there is a more cost effective way of sending money to the national centre than doing it by cheque. Just send an email to [financesupport@mssociety.org.uk](mailto:financesupport@mssociety.org.uk), copying in the branch chairman, giving details of the amount as well as how you would like the monies spent (for example, whether you would like the funds earmarked for research, the helpline, short breaks or to support the general work of the MS Society). The MS National Centre will then arrange the transfer into the appropriate national office bank account.

This makes the transfer process easier and saves the Society postage, interest and charges.

## Online branch accounting system update

### What is branch accounting? (a reminder)

Branch accounting is a web-based package which allows branches to maintain their accounting records online. As branch accounting is linked to the MS National Centre's accounting package, branches using the system will not have to complete an annual branch accounts pro forma.

During the summer a number of branches have been piloting branch accounting online

with many of the branches impressed with how easy and simple it was to use.

### How does it work?

Branch Treasurers can log in to the system through the Society's website. Your bank statement from Barclays is automatically uploaded onto the accounting system so you will be able to analyse these transactions. You will account for transactions on a 'receipts and payments' basis and therefore there will be no accruals or debtors.

The system will produce reports that can be used at your monthly branch committee meetings.

### Can I start using it?

The majority of branches can start using branch accounting online with the only exception being branches with shops. Branches with large day centres are also not currently recommended to use the system although we are assessing its suitability with a branch that has a large day centre.

To start using the online system, contact the branch accounts team at the MS National Centre on [financesupport@mssociety.org.uk](mailto:financesupport@mssociety.org.uk). Branches that start using the system from January 2013 will not have to complete a branch accounting pro forma for 2013.

As the system is so new, we still advise branches to keep your accounting records so that you can easily re-create a cash book if there are problems with the system.

# Finance

## 2013 Treasurers' forum preferences

Each year the Finance Department hosts a number of Treasurers' Forums which will give you the opportunity to receive financial training to help in the running of your branch and gain a better understanding of the treasurer's role.

The forums are not just suitable for treasurers, but as finances are the responsibility of the entire committee we would like to extend this invitation to any committee member that would like to attend.

The training will cover all of the essentials, from maintaining financial records to completing the annual pro forma, financial controls, use of funds, gift aid and any other financial topics of interest. We are also excited to offer an introduction to the new branch accounting software. It will also be an opportunity to meet other treasurers and committee members.

The forums are provisionally planned for June-September 2013 in the following locations:

- MSNC London
- York
- Birmingham
- Bristol
- Peterborough
- Manchester
- Guildford

The final locations chosen for the forums will depend on the level of interest shown in attending.

To register your interest and to state your preferred location please contact us at [financesupport@mssociety.org.uk](mailto:financesupport@mssociety.org.uk) or 0208 438 0709 and 0208 438 0785. Further information and details of the events will be sent out in the new year.

# For England

## England Council: new members and meeting dates 2013

England Council welcomes four new members in 2013. David Denholm (Hampshire & Islands); Ian Howells (Kent); John Josephs (North of England) and David White (Cheshire & Merseyside, co-opted for one year).

England Council will meet five times in 2013. Members are welcome to attend meetings – just get in touch at least two weeks in advance. The 2013 dates are:

- Friday 8 and Saturday 9 February
- Wednesday 17 April
- Friday 7 June
- Saturday 8 June  
(England Council annual meeting)
- Thursday 29 August
- Tuesday 29 October

For more information, please contact Lucy Tennison on 020 8438 0765 or at [englandcouncil@mssociety.org.uk](mailto:englandcouncil@mssociety.org.uk).

**Don't forget** – the updates in the first six sections of Teamspirit are for everyone, wherever you are in the UK. This issue includes information about our 60th anniversary and how you can get involved as well as other news affecting you. See pages 2-18.

# For England

## Regional Events

To cover period from beginning of January to end of February 2013

### North

Saturday 2 February	MS Support training day 1 (North West, Cheshire and Merseyside)
Friday 15 February	MS Support training day 1 (Yorkshire & the Humber)
Saturday 16 February	MS Support training day 2 (Yorkshire & the Humber)

### East

Tuesday 15 January	MS Support training day 4 (Herts. Essex & Beds)
Thursday 24 January	MS Support training day 3 (East Anglia)
Thursday 7 February	MS Support training day 4 (East Anglia)

### London & South East

Saturday 19 January	MS Support training day 4 (Surrey & Sussex)
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### West

Saturday 26 January	MS Support training day 1 (Wessex & West)
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If you are interested in the support volunteer role, please contact your local staff member. If you are a support volunteer and you have not yet attended the training session(s) you are interested in attending, please email [volunteertraining@mssociety.org.uk](mailto:volunteertraining@mssociety.org.uk) to request a booking form.

For all other events, please contact your local staff member for more information and to book a place.

# For Northern Ireland

## Research and Benefits Updates

### Would you like to learn more about our exciting research programme?

We're hosting two research updates to give you the opportunity to hear more about the research we fund, how you influence our research priorities and the latest groundbreaking achievements that could mean real changes for people with MS. We will also be providing an update on changes to benefits and information about applying for Employment and Support Allowance.

### Dates and venues:

- Saturday 2 March 2013 from 11am-1.30pm, Dunsilly Hotel, Antrim
- Saturday 9 March 2013 from 11am-1.30pm, Silverbirch Hotel, Omagh

For information or to register please contact Mark Hatte on 028 9080 2802 or [nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk).

## MS Support in NI

Eighteen volunteers have completed all four days of the first round of training in our support volunteer programme, and a further 13 have attended part of the training. Following a support area forum a number of volunteers have now been assigned to their local branch to provide support as part of the team.

The volunteers are in the process of meeting with the local branch committees in their areas. Local branches will further induct these volunteers with regards to local services and support.

The second round of recruitment has taken place and a total of 11 new volunteers attended the first day of training on 23 October. A training schedule to incorporate the remaining three training days will be set in the early part of 2013 for these new volunteers and existing volunteers who may have been unable to attend one of the four days. If you require further information regarding the Support Volunteer Programme please contact the Development Team on 028 9080 2802 or email [nidevelopmentteam@mssociety.org.uk](mailto:nidevelopmentteam@mssociety.org.uk).

# For Northern Ireland

## MSSNI Fundraising Events 2013

2013 is a very special year for the MS Society and to mark our 60th year we are planning a series of events. We would encourage our branches to get involved. Joining our events programme means that you can raise funds with little or no need to worry about organising the events yourself. Some of our tried and tested favourites like our abseils, zip line, ladies lunch, fire walk and our Slieve Donard Dander, will all feature in 2013 but we are also adding a number of new events including an 'Open' golf event and an 'It's a Knockout' event for companies.

There will of course be a number of other events organised to mark our 60th anniversary and we will update you in due course.

As part of our anniversary planning we would like to establish a 'Fundraising Planning' group and we would like each branch to nominate a member to meet quarterly to discuss ideas and events, and to help with future planning. We will be in contact in the near future to discuss your branch representative. Meanwhile, a huge thank you for all that you do to support our fundraising efforts.

If you are planning any special anniversary events for 2013, we would like to hear from you. Please contact Tom Mallon, Fundraising Manager on 028 9080 2802 or [tmallon@mssociety.org.uk](mailto:tmallon@mssociety.org.uk).

## Northern Ireland Council: new members and meeting dates 2013

We are pleased to welcome three new members to the Northern Ireland Council: Iain Crosbie, Tom Hunter and Margaret Fry, who were elected at the MS Society's AGM in September.

Iain is a member of the Belfast Branch and MS Society Research Network. Tom was diagnosed with MS in 2008 and since then has trained as a counsellor and volunteers at the MS Resource Centre. Margaret is the chair of the Larne Branch and has lived with MS for more than 20 years.

The NI Council meet regularly, and members are always welcome to attend meetings.

The 2013 dates are:

- 13 February
- 10 April
- June
- 28 August
- 30 October

Please note these dates are subject to change. Please contact Ann Wilson on 028 9080 2802 or [awilson@mssociety.org.uk](mailto:awilson@mssociety.org.uk) for more details.

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# For Scotland

## New director for MS Society Scotland

As referred to in the Board Update on pages 4-5, we're pleased to announce that Christine Carlin has been appointed as our new Director of MS Society Scotland. Christine was formerly employed by the Scottish Government at Deputy Director level. She had a wide range of challenging roles including a secondment to the Scottish Prison Service and as Head of Third Sector Policy for the Scottish Government.

Christine brings a wealth of experience and enthusiasm to her new role and I know you will all welcome her warmly. She will be starting work on 21 January, and will be in touch with Scotland branches directly soon after taking up the post.

Patricia Gordon, who has been Acting Director for MS Society Scotland over the past year, will be taking on a new role as Acting Chief Executive, following Simon Gillespie's departure on 15 February (Simon is taking up the Chief Executive role at the British Heart Foundation from April).

## Area Forums take off in Scotland

In the autumn of 2012, the MS Society hosted five area forums in Scotland. The peer led forums were an opportunity for the Society's local volunteers to network, share and learn. Representatives from the Scotland Council attended each forum and

heard from our branch committee members and other MS volunteers about what is important to them. Volunteers shared their experience of local projects, what worked well, and how these could be replicated.

All five forums were well attended and there were common themes running throughout.

Next year's forums will take place on the following dates (with locations to be confirmed):

- **Central:** 22 March and 27 September
- **Highlands and Islands:** 16 March and 12 October
- **East:** 15 March and 21 September
- **West:** 23 March and 5 October
- **North:** 6 April and 28 September

If you'd like to be involved in next year's Area Forums contact your Area Development Officer at [msscotland@mssociety.org.uk](mailto:msscotland@mssociety.org.uk) or on 0131 335 4050.

## Sharing good practice: Cumbernauld & District Branch links with MSPs and MP

"Part of our work as a branch is keeping MS on the map," says Jean Ford, Chairperson of Cumbernauld & District Branch.

With this in mind, the branch has forged links with its local MSPs and MP.

# For Scotland

The branch sends them their newsletter and invites them to take part in branch events. For example, during last year's MS Awareness Week, Gregg McClymont MP helped out on the branch's stand in Cumbernauld.

This gives local people affected by MS the opportunity to meet their political representatives face to face. "It then gives them the confidence to get in touch with their MSP or MP if they have an issue," Jean says.

In return, MSPs and MPs can see first hand how MS affects their constituents, gaining a better understanding of issues from changes to benefits to dropped kerbs.

Visits from MSPs or MPs have helped the Cumbernauld & District Branch gain coverage in the local press, raising awareness about MS and of the support that the branch provides.

## Getting in touch with your MSP or MP

"We have found that MSPs and MPs are very willing to get involved," Jean says. "Don't be afraid to get in touch!"

You can find contact details for your MSP on the Scottish Parliament website: <http://www.scottish.parliament.uk/msps/177.aspx>

To contact your MP, visit <http://www.parliament.uk/get-involved/contact-your-mp/contacting-your-mp/>

## Scotland Council: new members and meeting dates 2013

We are pleased to welcome two new members to the Scotland Council: Cat Johnson and Gareth Marr, who were elected at the MS Society's AGM in September 2012.

You may remember Cat as the cover star of our MS Week 2012 report, *Fighting back: the ordinary people battling the everyday effects of MS*. Cat also gave a powerful account of her experience of MS at our MS Week Reception in Edinburgh.

Gareth has been a tireless fundraiser for the MS Society. His amazing achievement of raising over £100,000 for the Society was honoured at our Awards in 2012, where he was announced as MS Fundraiser of the Year. You can read an interview with Gareth in the winter edition of MS Connect.

The Scotland Council meet quarterly, and members are always welcome to attend meetings. The 2013 dates are:

- 25 February
- 29 May
- 28 August
- 27 November

Please contact Rosemary Hastie on 0131 335 4050 if you would like more details.



# For Scotland

## Report on Treasurer and Support Volunteer Forums

On 24 November two forums took place in Glasgow, to allow our volunteers to share their experiences.

### The Support Volunteer Forum

The first to be held in Scotland, the support volunteer forum was attended by 20 support volunteers and chaired by Scotland Council member Ann Barnes. The volunteers shared their experiences of providing support after having participated in the new support volunteer training. They also heard from a guest speaker from the Citizens Advice Bureau about welfare reform, a topic that generated many questions.

The group discussed how often they would like forums to be held in the future, suggesting that two should be held each year – one in central Scotland and the other elsewhere – with the group to decide topics to be discussed, and guest speakers who they would like to hear from.

### The Treasurers Forum

The Treasurers Forum was attended by 18 volunteers. It was chaired by Scotland Council member Angela McCormack.

The volunteers were given an overview of the Society's finances and the role of branch treasurers. This was followed by a demonstration of the new Branch Online Accounting System, a discussion about

systems, financial controls and gift aid.

For more information about volunteering and this year's forums please contact Lynda Boyce on 0131 335 4050 or email [lboyce@mssociety.org.uk](mailto:lboyce@mssociety.org.uk).

## MS Support Volunteer Programme in Scotland: an update

We are pleased to announce that 66 support volunteers were trained in Scotland in 2012. Further training is planned for 2013 and we will be contacting branches to discuss your needs for volunteer recruitment and how we can help.

Overall, 94 per cent of attendees said the training was excellent.

For more information about support volunteering, please contact Lynda Boyce 0131 335 4050 or email [msscotland@mssociety.org.uk](mailto:msscotland@mssociety.org.uk).

## Changes to Operations Team staff

There are some changes to the locally based staff in the Operations Team as well as some changes to the branches that the Area Development Officers cover.

# For Scotland

We have recruited local **Service Development Officers (SDOs)**:

- **Cat Myles**: Cat will cover East and Central Scotland
- **Keith Park**: Keith will cover North Scotland, with a focus on Grampian. He will also cover parts of the Highlands and Islands, as required.
- Currently recruiting: West of Scotland. Initially, this post will focus on Glasgow city, where there is very little service provision and no branch activity.

## What will SDOs do?

They will represent the MS Society in local forums and groups aimed at improving services, such as influencing service delivery intentions of statutory authorities. SDOs will also work with branches and other volunteers to ensure that people with MS are involved in setting local priorities.

## What about Area Development Officers (ADOs)?

ADOs will be able to focus on supporting, developing and enabling local volunteers at branch level to meet minimum requirements and standards. They will also work with volunteers to develop and influence local volunteer-led service provision through peer groups and external partnerships.

## Your ADOs:

- **Paula MacGillivray**, previously the ADO for the North, Highlands & Islands, has now transferred to the vacant ADO post in the East.

- We are currently recruiting for Paula's replacement for the North, Highlands & Islands
- **Marion Dye** (ADO for Fife, Central and Tayside) will expand her remit to include the Cumbernauld Branch.
- **Darren Miller** (ADO West) will expand his remit to include the Wigtownshire Branch

For staff contact details, please contact the Scottish Office on 0131 335 4050 or email [msscotland@mssociety.org.uk](mailto:msscotland@mssociety.org.uk).

## Self management 2013

If you have MS, and would like to learn new skills to put you back in charge of your life, our self-management course might be just the thing for you.

Our course leaders, who all have a long-term condition themselves, will help you explore a variety of topics, from pain and fatigue management, exercise, relaxation and thinking techniques, communication skills and problem solving.

This course is free of charge, and consists of six weekly sessions, each lasting two and a half hours. To find out about courses in your area in 2013, please contact Ailsa Blair on [ablair@mssociety.org.uk](mailto:ablair@mssociety.org.uk) or 0131 335 4050.

# For Scotland

## Edinburgh Marathon 2013 – recruit your runners now!

With the start of a New Year, more people than ever will be putting fitness at the top of their resolutions list. What better way to get fit than running in an event at the Edinburgh Marathon Festival 2013?

Now is the perfect time for you to start recruiting runners to raise money for your branch in 2013.

In 2012, 119 MS Society runners took part in the Edinburgh Marathon Festival events and raised £55,345 to help people living with MS in Scotland. Recruiting runners for these events is an excellent way to reach new donors in your local area while raising funds for your branch.

Individual entries are now closed so runners can now only apply for a charity place. These applications must be submitted by mid-April and cost the branch a total of £140. After the big event, monies raised will be passed back to the branches that recruited the runner, minus the entry fee, for any charity place runners.

The Scottish Office will ensure that all branch runners have everything they need, including a running pack with a t-shirt and sponsorship forms.

We will send out recruitment packs in the coming weeks with further details on how your runners can join the MS Society Scotland's Team. In the meantime if you have any questions or want to register a runner now, please contact the fundraising team on 0131 335 4050 or [msfundraising@mssociety.org.uk](mailto:msfundraising@mssociety.org.uk).

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# For Wales

## Acting Director of MS Society Cymru

In November Joseph Carter, the Policy, Press and Campaigns Manager, was appointed Acting Director of MS Society Cymru during 2013.

Former Director of Cymru, Judi Rhys, has been appointed Acting Director of Operations following the departure of Barbara Williams, so Joseph will be leading the team in Wales during this time.

Joseph said: "I feel honoured to take on the role of Acting Director for MS Society Cymru and look forward to meeting branches and support groups throughout the year to find out about your issues and concerns. 2013 is an important year of celebration for the MS Society and I am keen to work with members to ensure that we maximise our impact and raise awareness about MS and the MS Society."

## Planned by me, not for me

Thank you to everyone who attended the 'Planned by me, not for me' reception at the National Assembly for Wales and helped make our event a success. Assembly Members were keen to hear examples of challenges in the social care system in their local areas, so we are grateful to the large number of branches who were able to attend.

The campaign continues into 2013 and we would like you to encourage members to write to their local Assembly Members to ask them to support our campaign. The more people who write to their local AMs, the greater the chance of ensuring changes to the law concerning direct payments and personal budgets.

Visit the flexible care page on our website at [www.mssociety.org.uk/flexiblecare](http://www.mssociety.org.uk/flexiblecare) or write to your AM at <http://bit.ly/YGP8YA>.

# For Wales

## MS Society Cymru Council: new members and meeting dates 2013

MS Society Cymru is pleased to welcome three new members to the Cymru Council: Stuart McLeese, Paul Robinson and Ian Williams, who were selected by interview on 14 June 2012.

Stuart McLeese, originally from Northern Ireland, works as a Barrister in Cardiff and has a relative living with MS. Paul Robinson works at Admiral Insurance in Swansea and has raised nearly £20,000 over the last four years as well as being instrumental in establishing the Twocann Tuesday Support Group in Swansea. Ian Williams from Pontypool, is a DJ and trainer for Able Radio has won an MS Society Award for his fundraising achievements. Ian has been 'the face' of many MS Society fundraising campaigns. All three Council members are keen to help steer the MS Society's work in Wales and are passionate about developing services to support the MS Community.

The MS Society Cymru Council meet bi-monthly, and members are always welcome to attend meetings.

The 2013 dates are:

- 9 February – South Wales  
(Future Inns Hotel, Cardiff Bay)
- 18 May – South Wales  
(Future Inns Hotel, Cardiff Bay)
- 5 July – North Wales  
(Ramada Plaza, Wrexham)
- 14 September – South Wales  
(Future Inns Hotel, Cardiff Bay)
- 9 November – South Wales  
(Venue TBC)

Please contact Matthew Witty on (029) 2078 6676 if you would like more details.

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# Classified Adverts

Please share these opportunities in your publications and networks.

## Balder Finesse chair and adapted vehicle

Balder Finesse F280 wheelchair comes with an electric seat raise, which can bring the user to the same eye level as those standing, as well as electric reclining backrest, tilt in space, and elevating leg rests. It is now on sale at £1,250 (Purchased for £12,900 including extras).

Wheelchair adapted Chrysler Grand Voyager 2001 (automatic) also available for £2,500. Converted to carry a wheelchair user, plus four people, it can also be adapted in ten minutes to a seven seat car. The car has been kept in a garage and has done 28,000 miles.

Due to changing circumstances, both the wheelchair and car are no longer of use to the owner, and he would like them to go to a good home. Realistic offers will be considered. For more information about either, contact Brian Wright on 02392 580 106 or [brianjwright@btinternet.com](mailto:brianjwright@btinternet.com).

## Lisnaskea

MS Society Northern Ireland has two fully accessible chalets available for hire at the SHARE village in Lisnaskea. The cost is £200 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](mailto: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. Bookings can be made by calling Richard Smith on 07709 235729. (Please leave a message if necessary and we will call you back.)

*Mention of advertisement by the MS Society of products or services is not an endorsement by the MS Society, its officers 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](http://www.mssociety.org.uk)

[www.facebook.com/mssociety](http://www.facebook.com/mssociety)

[www.twitter.com/mssocietyuk](http://www.twitter.com/mssocietyuk)

[www.youngms.org.uk](http://www.youngms.org.uk)

[www.facebook.com/childrenwithMS](http://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

## **Teamspirit**

MS National Centre  
372 Edgware Road  
London  
NW2 6ND  
020 8438 0944  
teamspirit@mssociety.org.uk