

Teamspirit

For group volunteers and national support group committee members



From top left to bottom right: Tamara and Dorothy who have volunteered with the Helpline for 15 years and the 25th birthday cake, the Helpline staff team, Helpline volunteers Christina and Helen, former Helpline volunteer Liz Matthews' beautiful painting gifted to the Helpline to celebrate their 25th year.

The MS Helpline is 25 this year!

Our Helpline is celebrating 25 years of providing support and information to people affected by MS all around the UK. We'd like to say a huge thank you to our dedicated volunteers who have given up their time over the years – we really couldn't do it without you!

The Helpline consists of 23 volunteers and 13 staff. Volunteers answered over 4,300

enquiries last year and, on average, provide over 60 hours of Helpline cover each week.

Here are some of the things our volunteers say about working on the Helpline...

"I enjoy the feeling I get... after speaking to someone. There's almost always a sense that I've helped someone. It may be in a tiny way, but I have helped."

"It's helped me a lot. It makes me feel like I'm doing something useful."



News and events

Local Networks Programme

Thank you to everyone who attended the May volunteer forums. We received helpful feedback on the Local Networks Programme and particularly the decision to move from local volunteer elections to a simplified selection process.




The majority of you were in favour of selection and while there were a range of views, most volunteers supported the proposal to attract new volunteers by calling branches “groups” and modernising the names of the lead local volunteer roles.

You told us you liked the menu of free fundraising materials now available from our online shop. Those of you using Web to Print and the Volunteer Portal fed-back that you found them easy to use and practical.

Moving forward, we’re improving access to group emails on mobiles and tablets, extending online accounting across all groups and simplifying the core requirements to run an MS group.

Starting this autumn we’ll roll out a simplified health and safety process for low risk activities. We’re developing new quality standards and guidance for local services and recruiting new Support and Wellbeing Facilitators to provide increased support for Support volunteers.

For further information please speak to your LNO or download this guide:
<https://volunteers.mssociety.org.uk/local-networksprogramme-guide>.

 **Audience:** All
 **Action:** Share
 **Contact:** Your LNO

Update on new website

In the last edition of Teamspirit we updated you on our plans to redevelop our website. We’d like to thank everyone who’s taken part in this project so far. Your ideas, contributions and time are hugely appreciated; you’ve helped us develop our plans and strategies.

Following detailed analysis of all this work, the budget requirements have come out higher than originally anticipated. We’ve therefore decided to make some short term changes to address immediate needs, while continuing to work towards and plan for larger website redevelopment in the future.

What does this mean?

This year, we’re going to rebrand our current website with our new logo, colours and font. We’ll also develop a new mobile-friendly fundraising microsite to make it easier and quicker to donate. This will increase income generation and enable us to make the most digitally of future events and campaigns, including MS Life.

At the same time, we’ll develop a business case to support the long term work on the new website and digital platforms. We’re hoping to restart work on the new website in early 2017 and build on the work that’s already been done.

 **Audience:** All
 **Action:** Share
 **Contact:** Alex Betti,
Head of Digital and Content
alex.betti@mssociety.org.uk
020 3828 6855



News and events

Group email accounts

As part of our commitment to ensure that everyone contacting our local groups gets the information and support they need, we've made a couple of changes to group email accounts. We're changing two features: the email signature and the auto response message. These changes are also key to data protection compliance, helping us to ensure that the personal data we hold is accurate, stored securely and not kept longer than necessary. These changes kicked in on 8 July.

The new auto-response message reads:
"Thank you for emailing our MS Society group. We have received your message. This inbox is checked on a regular basis. We will respond to you as soon as possible. If you have questions or concerns about MS, you can also contact the MS Helpline on 0808 800 8000. The Helpline is open Monday to Friday from 9am to 9pm (excluding bank holidays)."

We've added a line in your email signatures which states:

"If you no longer want to receive messages from us, please reply to this email with the word "unsubscribe" in the subject line."

If you receive a request to unsubscribe from a member you'll need to inform the Supporter Care team. If you receive an unsubscribe request from a non-member or other supporter, you'll need to amend your local records.

For further guidance on these changes and email use see: <https://volunteers.mssociety.org.uk/email-how-to>

 **Audience:** All
 **Action:** Share
 **Contact:** Supporter Care
supportercare@mssociety.org.uk
0300 500 8084

MS Life

MS Life 2016 is gearing up to be a great event. We've confirmed a programme of fascinating research talks, including a discussion around advances in neuroprotection with leading specialists. There are a variety of workshops to attend over the weekend, ranging from advice sessions on symptom management and work and benefits, through to demonstrations from top chefs in our MS Kitchen, and a chance to get involved in yoga, dancing, and many other accessible activities in our Get Active zone. The Spa will return this year, offering a chance for a little pampering! With some insightful talks in our Family and Carers zone, demonstrations from the ever popular Canine Partners, and interactive activities in our Science zone, there really is something for everyone at MS Life.

New this year, we're launching an MS Life app which you can use on your smartphone to keep updated on the programme as it develops, and put your questions to some of our speakers. With this app, you can still be involved in the event even if you're unable to attend!

MS Life takes place at London ExCeL on **17 and 18 September.**

MS Life 2016

ExCeL London 17-18 September

 **Audience:** All
 **Action:** Share, act – book your free place
 **Contact:** Conference team
www.mssociety.org.uk/mslife
0300 500 8084



News and events

Want to share your group's good news?

Send your story ideas to us at teamspirit@mssociety.org.uk and we'll be in touch!

A new MS Matters

We're currently working on the next issue of our membership magazine, MS Matters. The Summer 2016 issue will feature a preview of MS Life, giving you a sneak peak at some of the speakers and activities to expect at the event. We've got a bumper Research Focus section, bringing you all the latest developments, and inspiring interviews with two Paralympic hopefuls. MS Matters Summer will also have a new look and feel, in line with the new brand.

After the Summer issue, we'll be taking a slightly longer break than usual before bringing you the next issue in January 2017. This means there will be three issues in 2016 rather than the usual four. There are a few reasons for the change, but the main one is that we want to take time to look at how we can improve MS Matters and make it an even better magazine, with the MS community at its heart.

We plan to return to four editions in 2017. If you've got any questions about the change or comments on MS Matters, please let us know.

 **Audience:** All
 **Action:** Share
 **Contact:** Frances Whinder,
Managing Editor
msmatters@mssociety.org.uk

Christmas concert at St Paul's Cathedral

We're incredibly excited that a Christmas Concert will be held at St Paul's Cathedral on **Thursday 8 December 2016** to raise money for MS Society research.

You'll have a chance to be part of this unique and amazing event; tickets will be going on sale in September. Around 2,000 will be available, priced between £35 to £150. We'll let you know in the next Teamspirit how you can buy tickets.

Among those performing will be the St Paul's Cathedral choir, the gospel choir Soul Sanctuary and classical solo performers Sir John Tomlinson, Catherine Wyn Rogers, Gerald Finlay and John Mark Ainsley. Readings will take place throughout the concert, with the majority telling a story written by renowned screenwriter Abi Morgan (*The Iron Lady and Suffragette*) and performed by celebrities.

The concert will be broadcast live on the MS Society website and aired on Classic FM after the event.

 **Audience:** All
 **Action:** Share
 **Contact:** Fiona Foulkes,
Special Events Manager
fiona.foulkes@mssociety.org.uk



News and events

The EU referendum – what might it mean for people affected by MS?

Following the result of the EU referendum last month, we're considering what the 'leave' vote could mean for people living with MS and what should be prioritised in any future negotiations. We don't have all the answers – the impact of this is not yet clear, and nobody's sure what the future holds – but we're monitoring the situation, and will be ready to act and respond when needed.

Our priorities are:

Protecting public services If the predicted economic downturn leads to cuts to public spending we'll call on the Government to ensure people with disabilities do not bear the burden of these cuts.

Access to new treatments and devices There's a risk that access to new MS treatments or devices could be affected if the UK does not stay in the European Economic Area (EEA). This is because all medicines specifically licensed for MS in the UK are licensed by the European Medicines Agency (EMA), which avoids pharmaceutical companies having to go through separate licensing processes in each EU or EEA country. We urge the UK to stay in the centralised EMA system to ensure people with MS don't experience delays accessing new and innovative medicines.

Research funding and regulation The UK is one of the largest recipients of research funding in the EU. As negotiations move forward, it's critical the Government engages with medical research charities to ensure UK research continues to flourish.

Supporting the health, care and research workforces The Government should ensure that the health, care and research sector do not lose valuable and talented staff from the EU due to increased barriers to immigration.

Disability rights The EU has been influential in the development of disability rights laws that are hugely important for people with MS. We hope the Government will ensure disability rights affecting the thousands with MS are not eroded by any of these proposals.

What happens next?

The next Conservative leader will need to decide whether they trigger the legal mechanism for the UK to leave the EU and then negotiations can begin.

In this time of uncertainty one thing's for sure – we will continue to speak up for the interests of people living with MS wherever there's a need.

You can read Michelle Mitchell's blog about the potential impact of the EU referendum at <https://www.mssociety.org.uk/blogs>

Join our campaigns community at www.mssociety.org.uk/campaign

If you have any questions or concerns please contact Supporter Care.



Audience: All



Action: Share



Contact: Supporter Care

supportercare@mssociety.org.uk

0300 500 8084



Info and resources

Resources Update

New Factsheets

Seven new download-only DMT (disease modifying treatment) factsheets profile the 11 DMTs currently available to treat relapsing MS.

Each tells you:

- who can take the drug
- how you take it
- how good it is at controlling MS
- side effects
- the risks of taking it during pregnancy
- tests you'll need while you're on it
- support for when you're taking it

Withdrawn:

Getting the best from social care services has been withdrawn due to the many changes brought about since the Social Care Act 2015 came into effect. We're currently working on a new edition, which should be ready within the next five weeks. In the meantime please refer to the Social Care pages of our website.

Caring for someone with MS – a handbook for family and friends. This handy booklet has become outdated and is being reviewed with the aim to produce a new version in autumn.

Support and planning ahead – for people severely affected by MS has been withdrawn as the content is being reviewed. These issues will be covered in new resources issued towards the end of the year.

Updates

We've updated two of our publications:

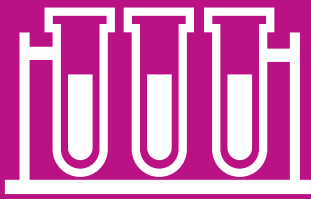
Motoring with multiple sclerosis

Hot and Cold: the effects of temperature on MS

Both are available from the online shop. We've changed the format of our leaflet *Grants from the MS Society* to download only and have cancelled any back orders we've received.



 **Audience:** All
 **Action:** Share
 **Contact:** Information Resources team
shop@mssociety.org.uk
020 8438 0999



Research

My MS My Needs

We'd like to say a big thank you to all of you who took the time to complete our latest version of the My MS My Needs questionnaire.

In 2012, the My MS My Needs survey helped us uncover the MS postcode lottery, and formed the basis of our Treat Me Right campaign.

In February this year, we launched the second My MS My Needs survey to learn if things have improved. We received a record number of responses, with over 11,000 people with MS adding their voice: that's nearly 1 in 10 people with MS in the UK completing the survey – a fantastic achievement!

Thank you to all the volunteers, groups and individuals who made this happen.

The results

At the end of this month, we'll be publically sharing the results of questions focused on treatment and access to specialists. Although there's still data to analyse, we've found that there's still work to do to ensure people with MS are receiving the best possible care.

Join us – sign up to the Campaigns Community at www.mssociety.org.uk/campaign to be the first to hear about the news.



Audience: All



Action: Share, act – join the Campaigns Community



Contact: Campaigns team
campaigns@mssociety.org.uk

Cambridge Centre for Myelin Repair

We're pleased to let you know that we're continuing our support of the Cambridge Centre for Myelin Repair. As repairing damage to myelin is essential to the development of treatments that can stop MS progression, we are committed to raising £1.6 million over the next four years to fund the innovative and ground-breaking research happening there.

For over a decade, the Cambridge Centre has been one of the world's leading centres in the quest to understand and promote myelin repair. Among their many achievements, researchers at the Centre have identified molecules that act on the myelin-repairing cells in the brain, and uncovered a link between vitamin D and myelin repair.

Over the next four years, the researchers will delve deeper into understanding the biological process of myelin regeneration and investigate how ageing and lifestyle factors – such as diet and exercise – interact with this.

As MS symptoms can progress over several decades, it's important to understand the effect that ageing has on myelin repair. Having this knowledge will help the development of future treatments for the condition.



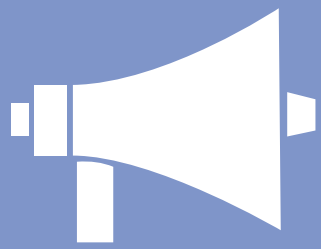
Audience: All



Action: Share



Contact: Research team
research@mssociety.org.uk
020 8438 0822



Fundraising

Thank you for your support!

We'd like to say a huge thank you to all the local groups that have been involved in supporting fundraising events so far this season. Whether it's been with promotion, supporting our participants ahead of the day, or being there to cheer them on at the side-lines – you've all been amazing!

From Scotland we'd love to say a special thanks to the Lothian group who supported the 'Living with MS' event in Edinburgh, running an information stall on the day (pictured below). Also, thank you to all our groups who held Cake Breaks! Our Ross-shire's group has so far raised a phenomenal £1,700 through Cake Break.



In June, Scotland co-opted Council member Lee Holland took on the Fourth Rail Bridge abseil. A big thank you to Lee and fellow Scotland Council member, Angela Monteith, who went along with her family to cheer on all our MS Superstars.

Thanks also to the Brighton group who came out to support the London to Brighton cycle (pictured below) back in September and also the Brighton Marathon. We'd also like to say a big thank you to the Stockport group for their support with the Great Manchester Run.



The Teesside group (who supported us on the day last year – thank you!) are looking for cheerers to support the Great North Run again this year, on **Sunday 11 September**. If you'd like to support with this event or any others in our calendar, please get in touch. We'd love to hear from you!

- Audience:** All
- Action:** Share
- Contact:** Supporter Care
supportercare@mssociety.org.uk



Fundraising

Direct Marketing update

Superhero appeal

Our appeal based on neuroprotective research landed with many of our members in early May. You'll have seen the appeal theme of 'Superheroes' promoted on the website and through social media. Thanks to your support the appeal has raised a fantastic £100,000 so far.

Raffle

Thank you to everyone who has already entered or donated to the Summer Raffle. There's still time to win one of 20 great prizes, including our £4,000 first prize! Tickets must be sent back by Friday 26 August or you can play online at www.raffleentry.org.uk/mssociety. We're aiming to raise £115,000 from this raffle to support our vital work.

Summer advances

The next edition of our supporter magazine, *advances*, lands this month, providing supporters with updates on how their donations and funds raised from events are making a difference. We received some very positive feedback after the previous edition and are hoping that the next one will continue to interest and inspire supporters.

If any of your members don't receive *advances* anymore and would like to be added to the mailing list, please ask them to get in touch.



Audience: All



Action: Share



Contact: Direct Marketing team
advances@mssociety.org.uk

Gift Aid reminder

In April 2016 HMRC updated the wording on the Gift Aid statement. This means that all old Gift Aid declarations are no longer valid to use.

The new Gift Aid declarations can be found in Appendix D of the Treasurers Handbooks on our website. Please use these declarations as failure to do so could put the organisation and your group at risk of failing an audit from HMRC.

If you need collection envelopes you can order these from Supporter Care on the number below.

We're here to help, so if you have any queries regarding Gift Aid please get in touch.



Audience: Treasurers



Action: Note



Contact:

Supporter Care: 0300 500 8084

Gift Aid queries: Finance Support team

financesupport@mssociety.org.uk



Finance

Finance support contact numbers

Please see below up to date contact details for any finance related queries. Please use these details to get in touch – we'll be happy to help!

For Branch Accounting Online & general accounting queries:

Chrish Ranjan, Branch Accountant:
020 8438 0711

Jamie Gracie, Divisional Accountant:
0131 335 4078

Email financesupport@mssociety.org.uk

For VAT related queries:

Samantha More, Tax and Trading Accountant:
020 8438 0779

For Barclays cash pooling queries:



Bindu Dudhia, Treasury Officer: 020 8438 0875
Anish Shah, Assistant Financial Controller:
020 8438 0796

Email treasurysupport@mssociety.org.uk

Barclays helpdesk (cheque books & statements):

0800 285 1040

Please note if you're contacting Barclays for the first time your call may be forwarded to the Finance team at MSNC for security reasons.

 **Audience:** All, especially Treasurers
 **Action:** Note

Finance Forums 2016

We're planning to hold Finance Forums this year to give local groups an opportunity to receive financial training and updates to help in the running of the group. All committee members are welcome to attend any of the forums. Dates and locations are:

- **28 September 2016**
Cardiff – MS Society Cymru (Temple Court)
- **30 September 2016**
London - MS National Centre
- **17 November 2016**
Edinburgh – MS Society Scotland (Ratho Park)
- **19 November 2016**
Hinckley – venue tbc

We'll be sharing further details in due course. If you'd like to attend or would like further information please get in touch.

 **Audience:** All, especially Treasurers
 **Action:** Act – get in touch if you'd like further information or to attend
 **Contact:** Finance Support team
financesupport@mssociety.org.uk
020 8438 0711 or 0131 335 4078



Branch Accounting Online – making the move

As part of our Local Networks Programme we're working to assist all groups to move to our internet based accounting system, Branch Accounting Online. By the end of 2015 more than two thirds of groups had successfully made the move to online accounting. With more groups moving to this method of accounting as the year progresses, we'd encourage your group to join them.

Key features of the system are:

- **Flexibility** – access via the internet anywhere and at any time, viewing and editing transactions on the go.
- **Simplicity** – you don't need to be an IT expert, you only need to analyse transactions as they appear on the bank statement; we'll do the rest.
- **Professional reports** – the system has custom made reports which can be exported to Excel and meet the reporting needs of all group committees.
- **Multiple users** – several committee members may access the system, so if your treasurer is unavailable, someone else can edit transactions or produce reports.

- **Calendar year** – groups no longer have to calculate estimate figures for November and December as the system runs from January to December.
- **Dedicated support** – the Finance Support team are on hand via phone and email to assist you. We can see exactly what you can see on your computer so we're able to assist you quickly.

Feedback from groups using the system is very positive so please do get in touch if you'd like to make the move!



Audience: All, especially Treasurers



Action: Act – get in touch



Contact: Finance Support team

financesupport@mssociety.org.uk

020 8438 0711 or 0131 335 4078



Support

Disability Law Service

Did you know that we partner with the Disability Law Service (DLS) to provide a specialist legal advice service just for people affected by MS?

The service covers England and Wales at present and is free and confidential. The areas of law covered are:

- Employment
- Welfare benefits
- Disability discrimination
- Goods and services
- Community care

The MS Legal Officer can't offer advice about criminal or family law and can't advise people living in Scotland or Northern Ireland. For support, advice and advocacy in Scotland and Northern Ireland, please visit the Disability Law Service website at www.dls.org.uk.

If you're in touch with someone who might benefit from this service, please do pass on the following contact details (it's always best for the legal adviser to speak directly with the person seeking advice):

Telephone: 020 7791 9800 (press option 1) – as the service can get very busy you may have to leave a message and wait for a reply.

Email: msadvice@dls.org.uk

If you have any questions, or would like some leaflets to distribute please get in touch.



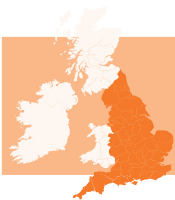
Audience: All



Action: Share



Contact: Janine Bennett,
Helpline Services Manager
janine.bennett@mssociety.org.uk
020 8438 0764



For England

MS Walk



Registration for this year's MS Walk will open soon! You can register your interest at www.mssociety.org.uk/ms-events/ms-walk.

Join us on **Sunday 25 September** – you can choose from three different routes, all starting and ending in the beautiful Battersea Park.

You can take our shorter, fully accessible route around Battersea Park which is just over 5k, or our medium route which is just over 10k and takes you further into London along the Thames (also fully accessible). For the more adventurous walkers, we have a longer 20k route that zigzags across the Thames up to Tower Bridge and back again.

We can't wait to see 1,000 people in orange t-shirts up and down the Thames – help us to make it happen!




 **Audience:** England
 **Action:** Share, act – register your interest
 **Contact:** Community and Events team
challenge@mssociety.org.uk

Southampton information event

The MS Society John Crawley Fund for Hampshire held a successful Information Day on 16 April in Southampton. The day's focus was on information about eating, drinking and swallowing, and 60 people attended. The event included a morning seminar led by local Speech and Language Therapists, and afternoon workshops for carers and people with MS to explore management techniques to alleviate swallowing difficulties.

The event was organised by Caroline Birch of the Lymington group, and was part funded by several groups across Hampshire. Caroline is already working with local staff to plan another event focussing on bladder and bowels later this year. We'd like to say a huge thank you to Caroline for her dedication in planning these highly regarded events.

Joining with other local groups to plan information events like this can be a great way to share the workload and reach out to people across your area. Speak to your Local Networks Officer if your group would like to coordinate a similar event.

 **Audience:** England
 **Action:** Share
 **Contact:** Your LNO



For England

Women Against MS, London

Caring – Sharing – Empowering

Women Against MS are a group of volunteers who meet twice a year to provide information, support and a good time (there's always cake)!

Lead Volunteer, Carol Carey says, "If you're a woman affected by MS, we're here for you. Some years ago we realised that there was a need for a support mechanism for women affected by MS, which provided an opportunity to off load and talk, about something or nothing! In 2013, we launched at Hampton Court Palace, and we continue to meet twice a year around International Women's Day (8 March) and in September/October.

Our meetings have been at lovely locations including Hampton Court Palace and City Hall. Our events have featured interesting speakers including CEO Michelle Mitchell, MS Society Chairman Hilary Sears and Jo Johnson, author of 'Shrinking the Monster'. We've also had two consultant neurologists talk about symptoms and MS research. There have been events on diet, cooking and our next event is about exercise and physio.

You can find out about our upcoming events and how to book on our Facebook page and Twitter. If you'd like to get in touch please email or call on the details below so we can respond in confidence.

We look forward to seeing you soon!"



Audience: England



Action: Share, act – get in touch with Women Against MS



Contact: Carol Carey, Lead Volunteer

info@womenagainstmis.org.uk

020 8542 1712



For Northern Ireland

End The Wait campaign – thank you for your support

As the dust settles after finding out who has won seats in Stormont and who the new Ministers are, we can reflect on the highlights of our End The Wait Campaign.

Waiting times were a key topic for most of the parties during the election. With your support we highlighted the impact extensive waiting times have on people living with MS.

Nearly a third of all candidates running for election pledged their support for End The Wait. We hope the newly elected MLAs who supported the campaign will champion our cause at the Northern Ireland Assembly. Thank you to everyone who emailed their local candidates encouraging them to pledge their support.

Telling your stories

After a successful campaign launch in February, we held two hustings in Londonderry and Belfast. Over 50 people questioned 11 candidates from across the political spectrum, covering issues such as health, social care, welfare, employment and transport.

Many people engaged with **#EndTheWait** on social media. The real life stories of people affected by the long waiting times for neurological services were shared, liked and retweeted lots of times.

What's next?

Now that the Programme for Government has been published for consultation, we'll be assessing its potential impact on the lives of people affected by MS.

We'll also be re-establishing the All Party Group on MS at Stormont and seeking a meeting with the newly appointed Health Minister Michelle O'Neill to discuss the issues you raised with us during the End The Wait campaign.



Audience: Northern Ireland



Action: Share



Contact: Jenny Ruddy,
External Relations Officer

jenny.ruddy@mssociety.org.uk



For Northern Ireland

Upcoming fundraising opportunities

We have a number of fundraising events in the diary and we'd like to invite your group to get involved. We take care of all the difficult bits – the event organisation and management, the admin etc. – all you have to do is recruit some MS Superstars to represent and raise funds for your group.

Our very popular Slieve Donard 'Moonlight Walk' will start on **Saturday 13 August**. We'll arrive at the top of Northern Ireland's highest mountain in the moonlight, when the views will be absolutely stunning. Places are filling up fast for this event so if you or someone you know is interested please do get in touch soon.

New for 2016, is our 'Adrenalin Rush' event. The perfect challenge for any adrenalin junkies out there! This takes place at Todd's Leap near Ballygawley, Co. Tyrone on **Saturday 20 August**. Participants will have an opportunity to experience the 'Drop Zone', 'High Zip Wire' and the fabulous 'Giant Swing' all in one thrill filled session.

Our May 'Zip it for MS' event across the River Lagan in Belfast was a great success with 50 people registering and raising over £6,000 for the MS Society. So we're doing it all again on **Saturday 27 and Sunday 28 August**. Can you encourage a few daredevils to take the 'Zip the Lagan' challenge for your group?

 **Audience:** Northern Ireland
 **Action:** Share
 **Contact:** Samantha Creighton,
Community Fundraiser
samantha.creighton@mssociety.org.uk
028 9080 2802

Applying for local council funding

Did you know that your group could receive funding from the local council? Local councils often have money put aside, which they can assign to different causes – often twice a year.

To find out if your group may be able to apply for local funding visit your local council website or speak to a local councillor. If you have any questions or would like to find out more about local council funding and making an application please contact us on the detail below.

 **Audience:** Northern Ireland
 **Action:** Share
 **Contact:** Tom Mallon,
Fundraising Manager Northern Ireland
tom.mallon@mssociety.org.uk
028 9080 2806



For Scotland

Living with MS, Edinburgh

Thank you to everyone who made our Living with MS event in Edinburgh on 20 May such a great success. The day was a chance for around 100 guests to hear talks on the latest research, share ideas at workshops and chat to others affected by MS.

Becky Driscoll, Public Involvement Officer, presented a clear overview of the latest developments in MS research, highlighting topics such as stem cell therapy, exercise, fatigue management and the latest from clinical trials, including news of potential treatments for progressive forms of MS.




Professor Siddharthan Chandran gave a powerful talk about the exciting work of the world-leading MS researchers at the Edinburgh Centre for MS research.

Attendees on the day said,

“Professor Chandran’s talk was excellent, taking us beyond the information that is generally available. Being aware of this helps allay the frustration at nothing being available for secondary progressive MS.”

“My husband attended the event with me. I think it has brought us closer together. He found it helpful talking to other people with MS and their spouses. I feel ready to attend support groups now. I wasn’t previously.”

You can view some of the presentations from the day at <https://www.mssociety.org.uk/ms-events/living-ms-edinburgh>, or check out [#LwMSEdinburgh](#) on Twitter.

 **Audience:** Scotland
 **Action:** Share
 **Contact:** Conference team
conferenceadmin@mssociety.org.uk

Fundraising challenges coming up

There are lots of great events to take part in over the autumn months. Please help us spread the word in your area!

Kiltwalk

Join us at **Speyside Kiltwalk** on **14 August** or the **Edinburgh Kiltwalk** on **18 September**.

“The whole event was so rewarding!” says Danielle, who took part in the Glasgow Kiltwalk in April. “The best part has to be reaching the finish line after 26 miles and everyone cheering you on!”

Loch Ness Marathon – 25 September

We have places in the marathon, River Ness 10k or Corporate Challenge 10k.

Great Scottish Run

10k and Half Marathon – Sunday 2 October

With six separate races over the weekend, the Bank of Scotland Great Scottish Run is a fantastic opportunity for people of different ages and abilities to participate together.

The Kelpies Supernova – 12 November

At this 5km night time event participants can get up close to the stunning 30 metre tall, 300 tonne horses and see them all lit up!

 **Audience:** Scotland
 **Action:** Share
 **Contact:** Sign up at
www.mssociety.org.uk/scotland-events
msfundraising@mssociety.org.uk
0131 335 4050



For Scotland

Getting loud with our new MSPs

A big thank you to everyone who got involved in our 'Get Loud for MS' Scottish Parliament election campaign.

Of the 160 candidates who supported our campaign, 75 were elected. This means that well over half the Parliament has pledged to 'Get Loud for MS'!

All five party leaders also endorsed our election manifesto, and SNP and Labour made commitments to MS support and research in their manifestos. So we're in a strong position to engage with the new Parliament.

We've already had parliamentary questions and a parliamentary motion lodged around the campaign. Recently we held a discussion with other neurological charities and MSPs to raise the profile of neurological care and support in the Parliament.

Top of our agenda is meeting new MSPs and re-establishing the Cross Party Group on MS. We'll be working hard to keep MS care, support and research high on the political agenda.

You can help by writing to your local MSPs, or meet with them to raise the campaign issues. Visit <https://www.mssociety.org.uk/scotlandelection> to download our manifesto, or contact Niall on the details below. Join our Campaigns Community at www.mssociety.org.uk/campaigns

 **Audience:** Scotland
 **Action:** Share
 **Contact:** Niall Somerville, Policy, Public Affairs and Campaigns Manager
scotlandcampaigns@mssociety.org.uk

Save the date!

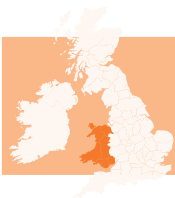
Welfare and benefits information event, 29 September – Glasgow

Living costs can mount up when you're living with MS.

Find out what benefits you can claim, and about the help that's available to you.

More information and how to book coming soon.

 **Audience:** Scotland
 **Action:** Share
 **Contact:** Lynda Boyce, LNO (Scotland – West)
lynda.boyce@mssociety.org.uk



For Wales

National Assembly for Wales Election

Thank you to everyone who's been involved in our campaign so far and contacted candidates in the run up to 5 May.

Of the 60 newly elected AMs, 47 pledged their support for our manifesto, giving us a real opportunity for them to champion our cause in the fifth National Assembly for Wales.

With your support we made access to treatment a key priority. Following the election and as part of the Plaid Cymru / Labour *Compact to Move Wales Forward*, a New Treatment Fund (NTF) is being developed.

The new Cabinet Secretary for Health, Wellbeing and Sport, Vaughan Gething AM (pictured below with Lynne Hughes, Country Director – Wales), has made it clear that the NTF will seek to ensure that new and emerging treatments are provided effectively and consistently across Wales.



Discussions around how the NTF will look are well underway and this affords us a real opportunity to influence what the fund will mean for people living with MS in Wales.

Prior to the election MS was highlighted as a condition which would benefit from the fund and we'll be working very closely with the Welsh Government to ensure this becomes a reality.

Our campaign continues and we'd like you to meet your AM either as a group or individually and let them know what it's like to live with MS. We'll be able to support you in doing this and can provide bilingual template letters for you to write to them about a meeting – so please do get in touch.

 **Audience:** Wales

 **Action:** Share

 **Contact:** Fiona McDonald, Policy, Press & Campaigns Manager – Wales
fiona.mcdonald@mssociety.org.uk
029 2167 8924



For Wales

People affected by MS meet social care leads

On 19 May, the South West Wales Service User and Carer Forum met with local social care leaders to discuss the implementation of the new Social Services and Wellbeing Act in South West Wales.

Simon Jones, Strategic Lead for the Social Services and Wellbeing (Wales) Act, Swansea Council and Amanda Aldridge, Community Independence & Wellbeing Team Manager, Bridgend Council, shared their plans to make sure social care services are more responsive to people living with MS and their carers. Forum members felt that the new approach of supporting people by focusing on what matters to them sounded very positive. All agreed that social care staff training and culture change was key to making this happen. Simon and Amanda committed to keeping in touch with the group about this.

The next meeting is likely to focus on engaging with the DWP (Department for Work and Pensions) in Wales with a focus on the accessibility of local benefit Assessment Centres.

If you're living with MS or care for someone with MS in South West Wales, and would be interested in joining this group please contact us.

We're also setting up a similar group in South East Wales – please contact us if you'd like more information on this.

 **Audience:** All
 **Action:** Share
 **Contact:** Fiona McDonald, Policy, Press & Campaigns Manager – Wales
fiona.mcdonald@mssociety.org.uk
029 2167 8924

Staff changes

Our Fundraising Manager Iestyn Evans has been on a sabbatical this year. MS Cymru has been extremely lucky that Lauren Swain joined us in his absence.

Iestyn returns in July and Lauren is moving to a new role with LocalGiving as part of their new Regional Development Programme which aims is to help 250 small charities explore online fundraising opportunities.

South Wales External Relations Officer Laura Courtney will be on maternity leave from early July. More information on Laura's maternity leave replacement will be circulated in due course.

Wishing Lauren and Laura all the very best in their exciting times ahead!

 **Audience:** Wales
 **Action:** Share
 **Contact:** Iestyn Evans, Fundraising Manager
iestyn.evans@mssociety.org.uk



Group contributions

Thank you to all groups for your contributions. They are all gratefully received.

Group contributions 11/04/2016 to 09/06/2016

Group Name	Earmarked Description	Earmarked	Research	General
Ballymena group			£8,000.00	
Ballymoney group			£5,000.00	
Bedford group			£5,000.00	
Brent group			£1,000.00	
Bury & North West Manchester group	Cambridge Myelin Repair Centre	£1,000.00		£1,000.00
Harrogate & District group	Helpline	£1,000.00	£3,000.00	
Merton group			£2,145.00	
Newmarket & District group	Cambridge Myelin Repair Centre	£15,000.00		
North Durham group	General			£3,500.00
Peebles group	Research Neuroprotection	£500.00		
Scunthorpe & District group	Cambridge Myelin Repair Centre	£1,500.00		
Sefton Area group	Newly Diagnosed Courses	£64.40		
Skipton & Craven group	Stem Cell Research	£2,000.00		
Skipton & Craven group	Cambridge Myelin Repair Centre	£2,000.00		
Skipton & Craven group	Exploring the role of genetic factors in MS	£2,000.00		
Stratford Upon Avon & District group			£1,000.00	
Surrey Branch			£5,000.00	
West Hertfordshire group	Cambridge Myelin Repair Centre	£5,000.00		
Yeovil & Sherborne District group			£3,500.00	
Total		£30,064.40	£33,645.00	£4,500.00



Classifieds

Accessible caravan

The North Surrey group has a two-bed accessible caravan with full veranda and wheelchair ramp access available for holiday hire based at Church Farm in Pagham, West Sussex.

The Rio Willoughby is a comfortable and stylish caravan specifically designed with the needs of wheelchair users in mind. It has a spacious lounge/diner, a kitchen with lowered work surfaces, a bathroom with walk-in shower and two bedrooms.

Church Farm is a 5* Haven site with a great entertainment schedule and two swimming pools. For further information, please email mscaravanpagham@hotmail.co.uk

Holiday Lodge

The North Norfolk group has acquired a new Boston Lodge at Burgh Castle, near Great Yarmouth, Norfolk, for people with MS, families and carers. The lodge sleeps six with a bed-settee in the lounge, a twin room with en-suite shower and a double room with overhead hoists running into a wet room.

The cost is from £300 from Saturday to Saturday. For park amenities please visit www.parkdean.com. For availability ring Sue on 01263 512689 or email justbobandsue@yahoo.co.uk

Holiday lodge and bungalow

The Bexley & Dartford group have a holiday lodge for people with MS and their families at Shorefield Holiday Village, Milford on Sea, near Lymington, Hampshire. The lodge is fully adapted for disabled people and wheelchair users, and has a master bedroom with en-suite shower room and hoist, a twin room, bathroom, and lounge/kitchen area with sofa bed.

The group also have a detached two bedroom bungalow at Eastbourne, Sussex, on a peaceful private estate close to Sovereign Harbour. Fully equipped (no fixed hoist) for people with MS and their families and furnished for 4/6 people.

For enquiries or bookings for both properties, please contact the Bexley & Dartford group on 020 8306 7050 or email bexley@mssociety.org.uk

Accessible caravan

Norwich & District group has a two bedroom accessible caravan for hire at Haven's Hopton Holiday Village which is 5 miles from both Great Yarmouth and Lowestoft, Suffolk with a brilliant sea view. For park amenities please visit www.haven.com/hopton

The cost is from £200-£400 per week Friday to Friday for 6 people, which includes passes for the leisure facilities. For availability or further information, please ring 01603 488561 or email mscentrenorwich@gmail.com

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



Teamspirit directory

Share these contact details in your group newsletter

Our offices

MS Society

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

MS Society Cymru

Temple Court
Cathedral Road
Cardiff CF11 9HA
020 8438 0700

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

Feedback on Teamspirit

Teamspirit

MS National Centre
372 Edgware Road
London NW2 6ND
020 8438 0848

teamspirit@mssociety.org.uk

Support groups

Asian MS

A national support group for Asian people with MS, their carers, friends and family
asianms@mssociety.org.uk

Mutual Support

For serving and ex-serving members of the Armed Forces and Reserves affected by MS, their dependants and carers.
support-team@mutual-support.org.uk

Find us online

www.mssociety.org.uk

<http://volunteers.mssociety.org.uk>

www.facebook.com/mssociety

www.twitter.com/mssocietyuk

Grants

020 8438 0700

grants@mssociety.org.uk

(all nations)

Get in touch

National MS Helpline

0808 800 8000

Membership

0300 500 8084

supportercare@mssociety.org.uk

Volunteering

020 8438 0944

Fundraising

0300 500 8084

supportercare@mssociety.org.uk