

# Teamspirit



Prime Minister, Theresa May, with Points of Light recipient David Allen, MS Society volunteer.

## No. 10 celebrates volunteers

**O**n 5 November 140 of our volunteers and supporters attended a reception hosted by Prime Minister, Theresa May, at Number 10 Downing Street.

The day celebrated advancements in MS research, and the incredible contribution our volunteers have made to support vital research in MS. Our Chair of Trustees, Nick Winser, spoke about the MS Society and our fantastic volunteers. Theresa May spoke about her personal experience of MS, the

MS community and progress to date.

You can see her full speech at [gov.uk/government/speeches/pm-speech-at-ms-society-reception-5-november-2018](https://www.gov.uk/government/speeches/pm-speech-at-ms-society-reception-5-november-2018)

Our Acting CEO, Patricia Gordon, and incoming CEO, Nick Moberly were there to meet volunteers and members of our MS community. The Prime Minister met with guests and also presented David Allen (pictured) with the prestigious Points of Light Award, in recognition of his contribution to the MS Society and our community.



The latest news and updates from across the MS Society. Perfect for sharing in your group newsletter.

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## Teamspirit looks different!

Teamspirit has had a little refresh. In September's edition we mentioned that we'd be changing the layout of Teamspirit in November. The content is still largely the same. But we've reassessed accessibility requirements for the visuals and changed the sections to hopefully be clearer and support you better in your roles.

### So where can you find what?

Our sections are now titled according to purpose:

- In the **Hope, help and voice** section you'll find article about things like our campaigns, research, and fundraising. This is news from across the MS Society so you know what's happening, and the difference we're all making. A lot of it will also be perfect for sharing in your group newsletters.
- In **Information for your group** you'll find just that! This is info to help you run your group, like policy updates, health and safety requirements and resources.
- **Support for volunteers** gives you the latest training, volunteer resources and information to support you in your volunteer role.
- Our **Finance** section isn't changing; giving you all your need to know finance info in one place.
- Our **Groups and services** section is for your stories, top tips and successes, making sure we're sharing your news with other groups.
- Our **Nations, Group contributions** and **Classified** sections have stayed the same.

### What do you think?

It's important that Teamspirit is as useful as it can be so let us know what you think. Does this new layout work for you? Is it clear? Could we make any other changes to the layout or look of Teamspirit?

**Contact:** Internal Communications team  
[teamspirit@mssociety.org.uk](mailto:teamspirit@mssociety.org.uk)

## Connecting through our local groups

*"Knowing that I can talk to a diverse group of people who understand the same issues I experience is unbelievably reassuring."*

We know that our local groups make a huge difference in local communities – connecting people and ensuring no one has to face MS alone. But we wanted to understand more about this, and the impact you – our groups – have on feelings of loneliness and isolation.

You may remember that in summer we asked people living with MS to complete a survey about this. A large number of people fed-back and the results really demonstrate the hugely positive impact local groups have.

Of the 58% of people who have felt isolated, 76% of them said that being part of a local group reduced this. And similarly, from the 60% of people who identified as having feelings of loneliness, 78% of these said that being part of a local group reduced this feeling as well.

### Connecting this Christmas

As part of our Christmas Appeal, we're highlighting the incredible difference our services make – connecting and supporting the MS community. Read more about connecting this Christmas on p3.



## Here for everyone this Christmas

It's the most wonderful time of year; when we think of others and connect with family and friends. But for some Christmas can be a difficult time of year. Together the MS community is here for everyone who needs us.

This Christmas there are so many ways you can connect.

### Donate to the Christmas Connections Appeal

We're hoping to raise over £200,000 to be there for people who need us most, not just at Christmas but all year round. You can get involved by donating at [mssociety.org.uk/spirit](https://mssociety.org.uk/spirit)



### Enter the Christmas Raffle

Enter the Christmas raffle and be in with a chance of winning £5,000! Every £1 raffle ticket you buy will be supporting people affected by MS. We're hoping to raise over £130,000. Enter online at [raffleentry.org.uk/mssociety](https://raffleentry.org.uk/mssociety). The draw closes on 20 December.

### Christmas Cards



Nothing sends festive cheer better than a card in the post! With 10 lovely designs (some of which are pictured here), our selection of Christmas cards has something for everyone. We've teamed up with Cards for Causes again this year so you can shop for cards online or with over 300 stores across England, Scotland and Wales visit your nearest shop. Find out more at [mssociety.org.uk/get-involved/fundraise/christmas](https://mssociety.org.uk/get-involved/fundraise/christmas)

**Contact:** Molly Amson Knight,  
Direct Marketing Officer  
[molly.amson.knight@mssociety.org.uk](mailto:molly.amson.knight@mssociety.org.uk)



## Access to medicinal cannabis restricted

Together we've been campaigning for cannabis for medicinal use to be legalised for people with MS who could benefit.

On 1 November, the law changed so that cannabis for medicinal use is available for prescription in the UK.

This a brilliant achievement, and the MS community played an important role in bringing about this change.

However, while specialist doctors are now able to prescribe cannabis-based treatments, we're concerned that nothing will change in the short term for the one in 10 people with MS who could benefit.

We're concerned that doctors are being discouraged from prescribing medicinal cannabis. New interim guidance for specialists doesn't recommend medicinal cannabis for pain, and doesn't address spasticity in MS – a symptom which can help be alleviated by cannabis.

We're calling for the interim guidance on prescribing medicinal cannabis to be urgently reviewed so that access to the treatment isn't so heavily restricted.

The National Institute for Health and Care Excellence (NICE) have started consulting on the long term guidelines for who should be able to access medicinal cannabis and we'll be working to make sure people with MS are involved in this process.

**Contact:** Campaigns team  
[campaigns@mssociety.org.uk](mailto:campaigns@mssociety.org.uk)

## Ocrelizumab for primary progressive MS

Over 21,000 people have called for a treatment for primary progressive MS to be made available.

In September, the National Institute for Health and Care Excellence (NICE) rejected ocrelizumab being made available for early primary progressive MS. This was because they think it costs too much for the benefits it can provide.

As a result, we launched a petition calling for the manufacturer Roche, NICE and NHS England to put patients first and agree a deal to make ocrelizumab available at a price the NHS can afford.

It didn't take long for thousands of people to join the call and within a few weeks the petition had over 21,000 signatures. Thank you to all of you who signed the petition.

This isn't the end. The significance of this treatment cannot be understated.

We'll be doing everything we can to ensure the drug is available to everyone who could benefit. We want to reverse the decision, or find alternative routes to access.

To get involved and find out more please join our Campaigns Community and add your voice. Visit [mssociety.org.uk/campaigns](https://mssociety.org.uk/campaigns)

**Contact:** Campaigns team  
[campaigns@mssociety.org.uk](mailto:campaigns@mssociety.org.uk)



## Runners up at BMA Awards 2018!

Five videos on exercises that relieve MS symptoms, filmed at our Belfast office, recently won runner-up in the 'Long-term Conditions' category in this year's British Medical Association's Awards for information for patients.

Physiotherapist Rachel Flynn and volunteers Derek McCambley and Kerstin Eikenberry, all in the films, accepted the award (pictured). You can see the films at [mssociety.org.uk/symptomsvideos](http://mssociety.org.uk/symptomsvideos)



Two other resources were highly commended in their categories. Our booklet 'Supporting someone with MS' and the 'Moving more with MS' booklet and exercise DVD.

### MS Trust Conference

Earlier this month we were at the annual MS Trust conference. It's a chance to showcase our information to around 300 MS nurses. Each year nurses take away over 3,000 of our booklets, factsheets, help cards and exercise DVDs.

## Speaking out against PIP 20 metre rule

On 17 October the MS community went to Westminster and Whitehall to speak out against the PIP (Personal Independence Payment) 20 metre rule.

### Trapped in 'PIPville'

We stood outside the Houses of Parliament in PIPville – population 9,400 – representing the people with MS who've already lost out on the higher rate of mobility support because of the 20 metre rule.

People with MS and members of our community sent a strong message to politicians. They held placards, and were tied to their houses – demonstrating the impact of the 20m rule taking away independence and trapping people in their homes.

### Over 36,000 people call for #ScrapPIP20m

Thank you to all of you who signed our petition. We handed in the petition – signed by 36,041 people – to the Department for Work and Pensions, calling on the Secretary of State for Work and Pensions to scrap the rule.

The PIP 20 metre rule is the main reason people with MS are losing the support they need, and the UK Government have still provided no evidence for it. As PIP continues to be rolled out, we could see a further 6,400 people living with MS lose out to higher rate mobility support. We'll be continuing to call for this rule to be scrapped. If you'd like to support the campaign by meeting your MP, please get in touch with the Campaigns team.

**Contact:** Campaigns team  
[campaigns@mssociety.org.uk](mailto:campaigns@mssociety.org.uk)

# Information for your group



Key updates and information to help run your group.

## Information resources update

### New resources

#### Updated DMT booklet

The print version of this booklet is available again. A new cover makes it easy to identify this latest version. A section on stem cell therapy, cladribine and an update on ocrelizumab have been added. Its order code remains the same (BK03).



Find it at [mssociety.org.uk/about-ms/treatments-and-therapies/disease-modifying-therapies](https://mssociety.org.uk/about-ms/treatments-and-therapies/disease-modifying-therapies)

#### Social care in Northern Ireland

Covering support you can get from Health and Social Care Trusts in Northern Ireland, this is the last of four booklets about social care in the different nations of the UK. Find them under 'care and support plans' at [mssociety.org.uk/care-and-support/health-and-social-care/social-care-services/about-social-care](https://mssociety.org.uk/care-and-support/health-and-social-care/social-care-services/about-social-care) or order from the online shop (code BK35 for the Northern Irish version)

#### Smoking factsheet

Following Stoptober, a new factsheet about the risks of smoking for people with MS is available to download at [mssociety.org.uk/care-and-support/everyday-living/smoking-and-ms](https://mssociety.org.uk/care-and-support/everyday-living/smoking-and-ms)

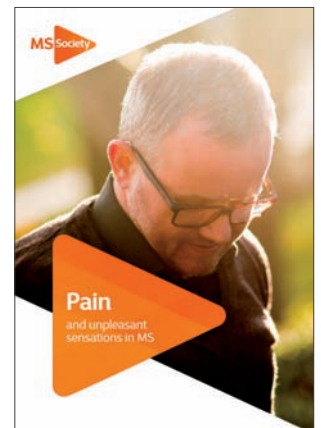
#### New cannabis factsheet

We now have a downloadable factsheet looking at how cannabis might help some people with MS, how it can be taken and what happens now the law has changed. Find it on our cannabis web page at [mssociety.org.uk/cannabis](https://mssociety.org.uk/cannabis)

### Updated resources

#### 'Pain and unpleasant sensations in MS'

This new pain publication has replaced Essential 17 'Pain and sensory symptoms'. Now in the new brand and format, its order code is BK29 for printed copies, or download at



[mssociety.org.uk/about-ms/signs-and-symptoms/pain](https://mssociety.org.uk/about-ms/signs-and-symptoms/pain)

All the publications above are available from the online shop. Please remove from circulation copies of the old publications that these new titles replace.

**Contact:** Carmel Barrett,  
Information Resources Manager  
[carmel.barrett@mssociety.org.uk](mailto:carmel.barrett@mssociety.org.uk)



## Note on membership renewals

December is often the busiest time for membership renewals and a lot of our members renew for two years at a time, paying the £10 fee in one transaction.

As we're reviewing our membership model at the moment we advise that you don't accept any payments that go further than the end of 2019. The new membership model may remove the cost of membership in 2020 so please accept payments only until the end of 2019.

If you have any questions, please get in touch.

**Contact:** Supporter Care  
[supportercare@mssociety.org.uk](mailto:supportercare@mssociety.org.uk)

## Reporting accidents and incidents

Over the last two years there's been an increase in the number of personal claims made against the MS Society following accidents. Lack of timely reporting has, in a small number of cases, made it difficult to defend these claims. When an accident or incident happens at a meeting or event attended by us whether it's a group event, national support group event or staff run event, it needs to be reported as soon as possible.

### Why do we need to do this?

- to meet national Health and Safety law
- it gives us the opportunity to review and improve our risk assessment system to better safeguard volunteers, staff and people living with MS
- it alerts groups doing similar activities so they can prevent accidents
- it enables us to give better support if a claim for compensation is made against a local group or the organisation (documented accidents provide evidence in these cases)
- it's a requirement of our insurers

Accident and incident forms are currently available on the volunteer website at:

<https://volunteers.mssociety.org.uk/health-and-safety-basics>

**Contact:** Your LNO



## Cyber-scams: how to stay safe

How do we keep personal information safe in this world of cyber-scams? Here are some top tips to help you recognise threats and stay safe.

### So what's what in cyber-scaming?

**Phishing:** When scammers pose as a trusted source, via fake emails, and request personal information, banking details or install harmful software on your device.

**Smishing:** Similar to Phishing but using fake text messages instead of emails. Sometimes including a link to a fake website and asks for personal information.

**Vishing:** When scammers call in person or via a recording and pretend to be a trusted source to trick you into giving personal information

**Ransomware:** Viruses that threaten to delete your files unless you pay a ransom.

### What should you do?

#### First, stop and ask:

- Am I expecting to receive this invoice or document?
- Does the sender's email address look correct?
- Is the web address secure? Any page asking you to input personal information should have a padlock symbol in the address bar and start with https, with correct spelling



<https://www.mssociety.org.uk/>

- Is the language clear and make sense?
- Is it offering something too good to be true?

### What to do next

- If in doubt, call sender to verify the email was from them.
- Don't click on links, download information or provide details.
- Don't forward and share.
- Report it to your LNO immediately and to the Data Governance team.

### What to do if you've made a mistake

Report swiftly – we have 72 hours to act!

- Call your LNO immediately and leave a message if you can't get through.
- Back this with an email to Data Governance. Please do not circulate documents that have personal data unless we ask for a copy.

### Information we'll need:

- Date and time
- A short description of what happened
- Number and type of people affected e.g. 10 non-members and 30 volunteers
- Categories of personal data i.e. emails, bank details etc.
- Any action you've taken to resolve the issue
- Any responses/complaints so far

Please do let us know if you're worried about anything or would like more information.

**Contact:** Your LNO and the Data Governance team

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





## Star appeal

Would support from a celebrity add value to your group's activities? Do you know of a celebrity who lives locally that you'd like to engage with? Or are you lucky enough to receive support from a famous face?

We have a fantastic group of high profile supporters and MS Society Ambassadors who have close personal connections to MS and do all they can to help raise funds and awareness of our work.

However, the majority of our celebrity supporters are based in London and the South East of England, and their busy schedules don't often allow them time to support activities further afield.

Next year we'll launch our Stop MS Appeal, which offers an exciting opportunity to reach out to celebrities to help us raise awareness and funds for MS research.

We'd love to hear from groups with connections to celebrities to explore if they might help us raise awareness of Stop MS, as well as our wider activities locally and across the UK.

We're also keen to assist you to secure support for your group activities from locally based celebrities. We're here to advise and approach on your behalf if needed.

Please do get in touch.

**Contact:** Lee Dainty,  
Celebrity and VIP Supporter Manager  
[lee.dainty@mssociety.org.uk](mailto:lee.dainty@mssociety.org.uk)  
020 8438 0733

## Updating our Online shop

In May's edition of Teamspirit we let you know we were starting work on improving our online shop system.

We know that the current system doesn't provide the best service and we need to improve it. Unfortunately the project has had a few delays and we want to apologise for the inconvenience this has caused for many groups. Thank you for your patience – we're back on track now and hope to launch an improved ordering system early in 2019.

In December we'll be testing the new online system before making it live, so we're looking for a few groups to help us. If you're interested in helping test the new system then please let us know by contacting Supporter Care.

Just so you know, when we introduce the new ordering system we'll need to take the old system offline first. The shop will be closed while we transition to the new system and information leaflets and fundraising materials will be unavailable to order. When we know the dates of this closure we'll let you know so that you can plan for this.

If you have any questions concerning our Online Shop project please get in touch.

**Contact:** Supporter Care  
[supportercare@mssociety.org.uk](mailto:supportercare@mssociety.org.uk)  
0300 500 8084



## Donating to research

Research into MS is a key priority for people affected by MS. As well as all the support you provide locally, your group may wish to contribute towards research, but what's the best way to do it?

### Donating to our research programme

Your group can donate to our research programme by emailing approvals with two group signatories to [financesupport@mssociety.org.uk](mailto:financesupport@mssociety.org.uk) and cc'ing your Coordinating team.

If you'd like your donation to go to a particular type of research e.g. progressive MS or symptom management, please let us know in your email.

Ideally you shouldn't be too specific or just specify one research project. It's in our best interest to get as much of our research programme as possible funded externally. We'll use any group donations last to top up any projects without enough external funding – so the more flexible your group is happy to be the better! If you'd really like to fund a particular research project then you can do so, but please also state an alternative project in case we get external funding elsewhere for your preferred project.

### **Please don't send money directly to researchers or universities.**

If your group would like to donate to research, the money can go to MS Society-funded research only. These research projects will have passed a thorough review before we agreed to fund it, helping us make sure that the research is of the highest scientific standard.

We also have audit and assurance processes in place to verify where the money goes to and the impact it has on people with MS. We want to make sure that every penny we spend on research will benefit people with MS.

If a researcher or university talks to you about donating to their research, please check with us that the MS Society has agreed to fund it. If we haven't, you won't be able to donate any money in the MS Society's name.

You can find a list of all the research we currently fund on our website: [mssociety.org.uk/research/explore-our-research/research-we-fund](https://mssociety.org.uk/research/explore-our-research/research-we-fund)

If you have any question please do get in touch.

**Contact:** Finance Support  
[financesupport@mssociety.org.uk](mailto:financesupport@mssociety.org.uk)



Latest volunteer resources, training and support.

## Fundraising planning for the New Year

As we approach a New Year, now is a great time to plan activities for 2019 and think about fundraising needed to run these.

Creating a fundraising plan now allows your group to prepare to meet the upcoming spend. Essentially, this is about working out what fundraising methods work best for your group and when, in the year, you'll deliver them. You can use a calendar to add the old favourites, like Cake Breaks and collections and then work out what else is possible. You may like to work over a longer period to plan and deliver a sponsored walk, or a black-tie ball. Your Area Fundraiser is on hand to provide advice and support for your fundraising planning. Please give us a call or drop us an email and we can chat through some tips for creating a useful calendar for next year.

### New banner available

Need new materials for your group fundraising events? The newest item to be added to our available materials is the Polythene Banner. It can be used both indoors and outdoors, e.g. as a backdrop for a stage or along a wall/railings outside a building, as 'on the day' advertising. Its re-usable and lightweight. You can order it under code MSSF-POLYBAN-ONE-18.

 **Contact:** Your Area Fundraiser

## An update on welcome and induction

A huge thank you to everyone who filled in the Welcome and Induction survey. The results are in and a group of staff and volunteers will be looking at them to decide next steps over the next few months. If you'd like to get involved in this group, let us know by emailing the Volunteering team. We've also been working on updating the statements in the current Welcome and Induction checklists so they're up to date with the changes that have happened over the last year. For example, fixing some of the links that changed when we updated our main website. Remember to download the checklist from the website so that you always have the most up to date version.

**Contact:** Volunteering team  
[volunteering@mssociety.org.uk](mailto:volunteering@mssociety.org.uk)

## Expenses guidance

We're creating guidance to support you when you're filling in your expense claim form. We're highlighting the areas that you've told us cause the most confusion when you're filling in your form. All volunteers are encouraged to claim their reasonable out of pocket expenses.

Next, we'll be working on a video that you'll find on our volunteer website. If you'd like to be involved in this video, please get in touch with the Volunteering team.

**Contact:** Volunteering team  
[volunteering@mssociety.org.uk](mailto:volunteering@mssociety.org.uk)



## GDPR eLearning update

Over the summer we launched the updated GDPR eLearning course, contacting 1,150 volunteers in roles, or using systems that handle the personal data of our community.

The law requires that training is provided to all relevant staff and volunteers and the quiz when passed is recorded so we can provide a training register should the Information Commissioners Office (ICO) ask for it.

Thank you to the 20% of you who've already completed the course, this is a great first step towards meeting this obligation.

Some people have experienced issues in accessing or being able to complete the course. There are two FAQ documents available that address the most common issues:

- How to access the eLearning system – [volunteers.mssociety.org.uk/gdpr-elearning-faq](https://volunteers.mssociety.org.uk/gdpr-elearning-faq)
- Troubleshooting guide – [volunteers.mssociety.org.uk/gdpr-elearning-talemtlms-troubleshooting](https://volunteers.mssociety.org.uk/gdpr-elearning-talemtlms-troubleshooting)

But please get in touch with us if these are no help.

Thank you also to those who have given feedback about the course. As a result, the Volunteer Learning and Development team are trialling a new eLearning system and hope to have an improved course available soon for those who've not managed to complete it yet.

**Contact:** Volunteer Learning and Development team  
[volunteertraining@mssociety.org.uk](mailto:volunteertraining@mssociety.org.uk)

## Group emails

Over 30 groups are already on their way with starting to use the new, personalised MS Society email function. The upgrade will include features such as mobile/tablet access, Microsoft online packages, shared document storage and calendar, and self-resetting passwords.

Volunteers in roles such as Group Coordinators, Finance, Administration, Communication and Support Volunteers; as well as accounts signatories are encouraged to upgrade as soon as possible. Lots of support, such as written guides and tutorials are available on the volunteer website to help you from start to finish.

The process is very simple. A volunteer from your group will need to contact the Volunteering team using this online form – <https://tinyurl.com/y8mc8jg6> and listing the volunteers who'd like an individual email account. These people will then be assigned the GDPR e-learning. As soon as that training is completed by all volunteers listed for your group, you'll begin your upgrade process!

We'll have more training sessions and videos available in December for all groups who are upgrading, so there is really no better time to get started!

For more information about the process and the new email upgrade, please see the volunteer website or contact the Volunteering team.

**Contact:** Volunteering team  
[volunteering@mssociety.org.uk](mailto:volunteering@mssociety.org.uk)



## Finance Year End

An email has been sent to all Finance Volunteers and Group Coordinators, advising on the information we'll kindly need you to provide on behalf of your group, for the financial year ending 31 December 2018.

If you have any queries or haven't received our email, please get in touch as soon as possible.

**Contact:** Finance Support  
[financesupport@mssociety.org.uk](mailto:financesupport@mssociety.org.uk)  
0208 438 0700

## Online Accounting: restricted fund or event?

Online Accounting allows you to record and monitor specific restricted funds and events. These can be recorded within the tabs across the top of your screen 'Restricted Funds' and 'Events'.

### What's the difference?

Restricted funds are generated in two ways:

1. A donor will specify that their donation should be used in a particular way
2. The MS Society has told the donor that a donation will be spent in a particular way

These truly restricted funds should be recorded under the 'Restricted Funds' tab, and applied to the relevant transactions to make sure they're reported correctly within our statutory accounts.

Group events and ring-fenced funds are not restricted funds and should only be recorded in the 'Events' tab.

If you need any corrections to be made please contact Finance Support.

**Contact:** Finance Support  
[financesupport@mssociety.org.uk](mailto:financesupport@mssociety.org.uk)  
0208 438 0700



## Depositing cash at your local Barclays branch

Barclays have made some recent changes in the way customers should deposit cash, to help against money laundering.

### What's changing?

From November 2018, Barclay's customers will be required to deposit cash at their local branch using a pre-printed paying in slip. The change mostly applies to personal and business accounts, and should **not** affect group corporate accounts held under the cash pooling scheme. However Barclays HQ have advised that the decision is down to the individual branch of Barclays as to whether or not you'll also be required to do so.

### What does this mean to us as a group?

When using the self-service devices, ensure that your volunteer or donor has a pre-printed paying in slip.

### Will the volunteer or donor be turned away if they don't have a pre-printed paying in slip?

No, cash deposits will continue to be accepted at the counter with or without a pre-printed paying in slip. It will however speed up the process of depositing cash into your group account, if you do so using a pre-printed paying in slip.

If you don't have a pre-printed paying in slip, just let the counter staff know that the cash is being paid into a 'charity corporate account'.

**Contact:** Treasury Support  
[treasury.support@mssociety.org.uk](mailto:treasury.support@mssociety.org.uk)  
0208 438 0700

## Contactless payment devices

It's been a while since we've been able to provide an update on the contactless donation boxes. This is because we've been narrowing down the search for suitable providers, and are now very close to making a decision.

We're aiming to offer the following options to groups:

1. One-off purchase of a contactless donation
2. Monthly rental of a contactless payment device

We'll announce the results in our January 2019 edition of Teamspirit, along with the pricing structure and details of how to place an order on behalf of your group.

**Contact:** Treasury Support  
[treasury.support@mssociety.org.uk](mailto:treasury.support@mssociety.org.uk)  
0208 438 0700



Sharing your stories, good news and top tips.

## Moray group get active together!

Our Moray Group in Scotland have launched a number of new opportunities to highlight the importance of keeping active and showcase what is already available in the local area.

The group launched **Anti-Gravity Treadmill** sessions in early October, in partnership with Move4ward, with 12 people signing up. The treadmill, one of only three in Scotland, uses air to unweight the person enabling them to move unrestricted and pain-free which can help restore and build muscle strength, range of motion, balance, function and fitness.

A four-week **Seated Yoga** introduction course was launched at the end of September, with 10 people registering to take part. With the help of our service starter-kit for yoga, the group identified a qualified and experienced teacher and venue.

The Moray group also worked with their local Curling Development Club and Moray Leisure to host an inclusive **Curling** taster session on 30 October with a four-week beginner course offered for anyone who wants to take it further.

And as if that wasn't enough they're hoping to plan a 'family day' which will focus on physical activity in mid-2019.

Keep up with the group's activities by following their Facebook page [@MSSocietyMoray](#).

**Contact:** Tracey Harrison,  
Development Lead – MSActive Together  
[tracey.harrison@mssociety.org.uk](mailto:tracey.harrison@mssociety.org.uk)

## MS Helpline named Helpline of the Year!

*"We're incredibly proud of the Helpline team, and it's fantastic that they've been recognised in this way."*

Ed Holloway, our Executive Director of Services and Support

Our fantastic team of volunteers and staff in the MS Helpline have won Helpline of the Year 2018 in the Helpline Partnership Awards.

Our Helpline, which took more than 18,000 calls last year, was recognised for the significant contribution made to the helpline sector and the wellbeing of those who use the service. The Helpline was also awarded second place in Helpline Innovation of the Year and volunteer, Aleks deGromoboy, won third place for Volunteer of the Year.

Ed Holloway went on to say,

*"Our dedicated staff and volunteers make a real difference to people with MS, their friends and families, and over the past year they've introduced more flexible ways for people to get in touch, including on social media."*

Abigail Stidston, Senior Helpline Support Officer said:

*"The Helpline are delighted to have received this recognition - it's hugely important to use. We have a fantastic team of staff and volunteers who are always striving to provide the best support to people affected by MS."*

Our MS Helpline is open Monday to Friday, 9am to 7pm except bank holidays. It's free to call from landlines and mobiles within the UK.

Huge congratulations and thanks to the MS Helpline team!



## Talking social care with the Care Minister

In September, people living with MS and other long-term conditions met with Care Minister Caroline Dinenage to discuss social care funding in England.

Right now, 1 in 3 people with MS aren't getting the care and support they need with essential everyday activities like washing, dressing and eating. We've been calling for the Government to provide urgent funding, alongside long-term solutions, so people with MS get the social care they need.

At the meeting, the Minister heard directly from people with MS about the problems they face. She acknowledged the short-term and long-term funding issues, and agreed the Government needs to take big decisions. This was encouraging to hear, but it was disappointing to see that the Government's subsequent Budget announcement only included £650m for social care – far from filling the £2.5bn funding gap needed to keep the care system afloat.

The next step is the Green Paper (public consultation) on social care, due before the end of 2018. This is a vital opportunity to shape the future of social care, and we'll be ensuring the experiences of people with MS are heard loud and clear by the Government.

You can find out more and get involved in our campaigns by joining the Campaigns Community at [mssociety.org.uk/campaigns](https://mssociety.org.uk/campaigns)

**Contact:** Campaigns team  
[campaigns@mssociety.org.uk](mailto:campaigns@mssociety.org.uk)

## New England council members

Following the AGM in September we're delighted to introduce our new (and not so new) England Council Members, starting in January 2019.

Re-elected as Chair of the England Council, is **Phillip Gamble**, based over Lancashire, South Cumbria and Greater Manchester. Following his wife's diagnosis over 20 years ago, Phillip has been involved in various positions volunteering with us.

**David Allen** was also re-elected. David is based in Hertfordshire, Essex and Bedfordshire. He ran a local group after being diagnosed with primary progressive MS in 1996. He's now campaigning and attends Westminster All Party Parliamentary Group (APPG) meetings.

Welcome to **Eve Darwood**, in the East Midlands. Following her MS diagnosis in 2014, she is completing a PhD on the ways blogs and poetry can narrate life with MS and writes a blog on her story. Eve is passionate about informing others about MS.

**Peter Hicks** will be joining us in the Hampshire and Islands area. He's volunteered in multiple roles. Peter was a full time carer for his wife and is a Local Ambassador for Carers UK.

And finally, welcome to **Dom Thorpe**, in London. Dom's mum lived with MS for many years, he helps people with MS with health and fitness. Following a series of fitness videos with us, Dom has now become part of our council.

We hope you'll join us in welcoming them all.



# For Northern Ireland



## NI Council

There have been three new additions to the Northern Ireland Council, they are:

**Philippa Watson** was diagnosed with MS in June 2017, aged 24. After receiving support from the MS Society, Philippa was keen to get more involved with the NI Council.

Passionate about our fundraising, awareness raising and campaigning work, Philippa is keen to make a difference.

With a background in business with a multinational company, Philippa will put those skills to use for the MS Society.

**Andrew Taylor** has a long personal experience of MS as his mother lived with MS. He was motivated to join the NI Council in recognition of the support his family received from the MS Society.

With professional experience in the pharmaceutical industry, Andrew's team worked on the development of ocrelizumab. He is enthusiastic about MS research and access to life-improving treatments.

**Ian Poultney's** experience of MS began as a 7-year-old while his mother was living with MS. With a personal history as a young carer, Ian is passionate about the services available to people with MS and their families including those offered by the MS Society.

Ian is an Adviser with the Citizens Advice Bureau supporting people on benefits entitlements and welfare rights. He also has experience as Chairman of the Board of Trustees for a number of charities.

A big welcome to all our new council members!

## Update on the recall

At the beginning of May the Belfast Health and Social Care Trust initiated a recall of 2,500 neurology patients after investigations into the treatment and care provided by a specific neurologist. The Trust committed to reviewing each patient within a 12 week period building extra consultant and diagnostic testing capacity in order to do so.

Throughout this time, we've been working hard engaging with the Belfast and Trust and the Department of Health representing both individual people affected and the wider patient group within the recall. Unfortunately, as a result of this process, we have been informed that some people have received life-changing news up to misdiagnosis. We continue to work to ensure everyone receives the care and support they need through what has been a very difficult time. There remain many outstanding questions on the circumstances surrounding the recall and decisions made before, during and afterwards. We'll continue to pursue answers for those affected.

As a result of the recall, a number of public inquiries have been announced. The first of these is seeking input from people who have experience of neurology services. If you'd like to submit your views on neurology provision in Northern Ireland visit [www.neurologyinquiry.org.uk](http://www.neurologyinquiry.org.uk)

The Department of Health has also announced a wider review of neurology which will determine the future of services and provision across Northern Ireland. We'll play an active role in this, fighting the corner of people living with MS. If you want further information on any of this work or want to share your own experience please get in touch.

**Contact:** NI reception  
[nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk)



## Christmas events

### Christmas Music for MS

Join us on Wednesday 12 December for our Christmas Music for MS event. This festive event will take place at Riddel Hall, Stranmillis Belfast.

Enjoy the sounds of the Renaissance Choir, festive readings and the obligatory hot chocolate and mince pies. Riddel Hall is the perfect setting, a Grade 2-listed red brick building, which has been sympathetically renovated to retain many original features.

It all makes for a fantastic festive event and we'd love to see you, your family and friends on the night. Who knows the big man in the red suit might even make an appearance.

Tickets for the event are just £10 and can be obtained from our Resource Centre.

### Santa Dash and Dander

It just wouldn't be Christmas without our Santa Dash and Dander. Many of our supporters see the Dash and Dander as the start of their festive season.



This year it takes place on Saturday 15 December at Stormont Estate with a 10.30am start. Come along and join us for this family event where you can enjoy dressing up as Santa and then Dash or Dander up and down the Avenue. The Avenue is close to 2 miles – and you can Dash or Dander at your leisure.

This is a great event for the whole family – even the pet dog can join in, provided they are kept on a lead and dress up as Santa too. Family registration for the event is £20 for 2 adults and 2 children, additional adults are £10 and children £5. Santa suits are provided on the day along with some festive refreshments and treats for the children.

**Contact:** NI reception  
[nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk)  
028 9080 2802



## Fundraising next year and 2020

We have some absolutely fantastic fundraising events organised for 2019 and 2020!

Please share these amazing opportunities with your communities and encourage people to get involved.

### Arctic Trek

We're thrilled to launch our first ever overseas trek! In January 2020 intrepid **#MSSuperstars** can join our team heading from Scotland to the Arctic.

On this unique challenge fundraisers will spend three days trekking in sub-zero temperatures – pulling equipment in a pulk and battling the elements.

This incredible journey will make a huge difference in helping to stop MS and give trekkers memories of a lifetime.

### Ziplide

Our award-nominated, fully accessible, Ziplide Zinger challenge is back for 2019. We can't wait to see our **#MSSuperstars** zip through the trees in beautiful Crieff on 27 April!

### Edinburgh Marathon Festival 2019

Places for the famous Edinburgh Marathon Festival 2019 are officially open and we are thrilled to be a Premier Affiliate Charity again this year. Come join our team on 25 or 26 May for a day you won't forget.

### Kiltwalk

Lace up your trainers, look out your orange top and throw on a bit of tartan for the Glasgow (28 April), Aberdeen (2 June), Dundee (18 August) or Edinburgh (15 September) Kiltwalks. Make your steps count!

**Contact:** Scotland Fundraising  
[msfundraising@mssociety.org.uk](mailto:msfundraising@mssociety.org.uk)

## Scottish Council Members

We are pleased to welcome four new Scotland Council members who will work alongside our staff and local groups to stop MS.

**Dorothy Robertson** was first diagnosed in 1997 and has been volunteering with her local group in Angus for two decades.

She is group coordinator and wants to promote awareness and understanding of rural issues to ensure people, wherever they are, get the best possible service.

**Jennifer Bryson** was diagnosed after years of poor health and found the support from the MS Society and her community invaluable, inspiring her to get involved.

A former committee member with the Scottish Association of Young Farmers, she's eager to use her experience to raise awareness and effect change.

**Laura Beveridge's** family has been affected by MS and she has seen how important it is that newly diagnosed people have access to accurate information and support.

She wants to energise and drive forward the MS Society agenda using her professional skills as an influencer and natural communicator.

**Linda Mason** is a returning Scotland Council member who was diagnosed in her late 20s and has been volunteering with the MS Society and Housing Association ever since.

Linda is her local Group Coordinator and wants to support and encourage volunteers to fundraise and keep a flow of new ideas.

Welcome to our new Scotland council members!



## Living Well with MS Virtual Sessions

We were delighted to launch our Living Well with MS virtual sessions in September, with funding from the RS MacDonald Charitable Trust, to support people newly diagnosed with MS living in rural and remote parts of Scotland.

Each session consists of four modules taking place over four weeks. Participants are sent supporting materials to consider before logging in virtually each week to chat with others who are recently diagnosed with MS. The aim of our sessions is to support people in sharing their experiences, feeling more confident to set up and achieve their daily goals, understanding 'self-management' and learning new skills to live with the condition.

One happy participant shared her experience of taking part: *"I met some lovely people and after each meeting I felt more positive about life and the future. I learned skills on how to manage time, fatigue, stress and other aspects to make life more manageable with MS."*

We're currently trialling the virtual sessions in Scotland and, if successful, we hope to offer them across the rest of the UK.

To find out more about our virtual Living Well with MS sessions please contact Self Management Lead, Coleen Kelly.

**Contact:** Coleen Kelly  
[coleen.kelly@mssociety.org.uk](mailto:coleen.kelly@mssociety.org.uk)  
0131 335 4050



## Update on grants

Since starting just over a year ago, our My MS My Rights My Choices project team have been busy supporting the MS community in Wales in a variety of ways including making grant applications.

So far, Adele, Sophie, Naomi and Tim have secured around £34,000 in grant funding for people living with MS in Wales who are in financial need. Over £13k of this has come directly from MS Society grants.

People have been granted money for items such as scooters, wheelchairs, home adaptations and accessible bikes.

We know only too well that people have less money than ever before. The grants we're able to support people with are helping to fill the gap.

Please help share information about the My MS My Rights My Choices project to support more people.

**Contact:** My MS My Rights My Choices team  
[mymscymru@mssociety.org.uk](mailto:mymscymru@mssociety.org.uk)  
0808 800 8000

## New Big Lottery funded project in South Wales

Being physically active is important but for many people living with MS there is a real struggle to access opportunities.

When we surveyed people living with MS in Cardiff, Merthyr and Rhondda Cynon Taf, 95% told us that they'd like to be more physically active but are prevented from doing so.

This is about to change thanks to the Big Lottery Fund.

MS Cymru has received a grant of £149,415 to run 'Active Together' - a two year pilot project to promote fitness and friendship for people in Cardiff, Merthyr and Rhondda Cynon Taf.

A project coordinator and administrator have been appointed and will be working closely with a steering group made up of people living with MS.

Ann Jones from Rhondda Cynon Taf was diagnosed with MS in 2001 and has been part of the project steering group. She said, *"Having properly trained instructors who know about the condition and how it can affect us will be so beneficial. We need exercise classes which adapt with a person's MS and are tailored and bespoke, so that when we are feeling well we are encouraged to move more and take it easier when we are having an off day"*.

**Contact:** Lynne Hughes,  
Country Director, Wales  
[lynne.hughes@mssociety.org.uk](mailto:lynne.hughes@mssociety.org.uk)



## New council members

We're delighted to welcome our new members to the Cymru council.

### Kathryn Foot

Kath's sister was diagnosed with MS in 2006 and three years later her mother was diagnosed with late on-set primary progressive MS.

Kath said; *"We were faced with a condition we knew little about, it was scary and emotional and we did not know where to turn. We then discovered the local group and realised we weren't alone. As a values-driven person it's important to give back, serving as a council member would enable me to do that"*.

### Glyn Furnival-Jones

Glyn was diagnosed with MS in 2004. He's an active member of the MS community in Cardiff helping with fundraising for the local group, campaigning to improve access to transport and supporting our media work. Over the past 18 months, Glyn has been working tirelessly alongside Sue Cox to set up the Cannabis4MSinWales Facebook group and successfully lobbying the Welsh Government.

### Jeanette Barton

Jeanie was diagnosed with MS in 2009. She is involved with her local community, and is currently a Community Councillor. Jeanie said; *"I found the MS Society a great lifeline and because of this I would like to become more involved by becoming a council member. I want to use my skills to help others with MS by being a voice and putting their needs and wishes to the MS Society"*.

### Howard Bishop

Howard lives with pancreatitis and Secondary Progressive MS. He's volunteered as a trade union steward where he defended people's rights, and never lost a case! Howard has been instrumental in setting up Boccia opportunities for people living with MS in Cardiff and arranging monthly social gatherings for younger people and their partners.

### Mark Carey

Diagnosed in 2003, being active in the MS community is very important to Mark. He's involved in campaigning on PIP, medicinal cannabis and employment rights; along with supporting the MS Society groups in West Wales and volunteering with the My MS My Rights My Choices project.

Many thanks to all our outgoing council members for all their amazing efforts over the years. Diolch yn fawr iwan.

**Contact:** Matthew Witty, Executive Assistant  
[matthew.witty@mssociety.org.uk](mailto:matthew.witty@mssociety.org.uk)  
029 2167 8921



## Fundraising in 2019

We're super excited about our fundraising activities coming up in 2019.

From sliding down a Zip Wire in North Wales to trekking 25 or 50km along the beautiful Brecon Beacons, there's something for everyone to get involved in.

- **8 June** – Velocity 2, Zip World
- **6 July** – TrekFest, The Brecon Beacons (25km or 50km routes)
- **15-18 August** – Wales End to End Cycling Challenge
- **Oct (TBC)** – Cardiff Half Marathon

Be part of the **#MSSuperstars** Cheer Squad!

The MS Cymru cheering squad at this year's Cardiff Half Marathon was one of the brightest and loudest there.

Join us at next year's Cardiff Half and the other events listed above – help us to be even louder and cheer on our amazing #MSSuperstars

**Contact:** Sian Dorward,  
Fundraising Manager for Wales  
[sian.dorward@mssociety.org.uk](mailto:sian.dorward@mssociety.org.uk)  
029 2167 8920

# Group contributions



A big thank you to all groups for your contributions. They're all gratefully received.

Group contributions 02/08/2018 to 03/10/2018				
Group Name	Earmarked Description	Earmarked	Research	General
Angus group	Stem cell research	10,000.00		
Bridgend & District Group	Stem cell research	1,000.00		
Bridgend & District Group			1,000.00	
Kings Lynn & District group	Cambridge Myelin Repair Centre	10,000.00		
Moray group				1,000.00
North Cornwall & West Devon Group			5,000.00	
Northamptonshire Group			10,000.00	
Preston group			2,500.00	
Scunthorpe & District Group	Progressive MS Research	3,000.00		
<b>Total</b>		<b>£24,000.00</b>	<b>£18,500.00</b>	<b>1,000.00</b>





## Share chalets

The team in Northern Ireland have two fully accessible chalets for hire at the Share village in Lisknaskea on the tranquil shores of Upper Lough Erne in beautiful County Fermanagh.

Share is an outdoor activity centre open to everyone and with plenty of entertainment options for the whole family. Share works for the inclusion of disabled and non-disabled people by providing opportunities for all to participate in a wide range of recreational and creative activities.

We're able to offer our chalets at a much reduced rate to people with MS and their families. Our chalets sleep eight and come with access to the onsite fitness centre.

To find out more please contact NI reception at [nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk) or on 028 90 802 802.

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



## Our offices

### MS Society

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

### MS Society Cymru

Baltic House  
Mount Stuart Square  
Cardiff CF10 5FH  
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@mssociety.org.uk](mailto: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](mailto: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](mailto:support-team@mutual-support.org.uk)

### Women Against MS

Confidential support for women who have MS, their carers, families, friends and employers. Currently holding two information events a year.  
[info@womenagainstms.org.uk](mailto:info@womenagainstms.org.uk)  
020 8542 1712

## Find us online

[mssociety.org.uk](http://mssociety.org.uk)

[volunteers.mssociety.org.uk](http://volunteers.mssociety.org.uk)

[facebook.com/mssociety](https://facebook.com/mssociety)

[twitter.com/mssocietyuk](https://twitter.com/mssocietyuk)

## Get in touch

### Supporter Care

[supportercare@mssociety.org.uk](mailto:supportercare@mssociety.org.uk)  
0300 500 8084

### National MS Helpline

[helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)  
0808 800 8000