

# Teamspirit



## Investing in our volunteers

**W**e couldn't do what we do without you – our fantastic volunteers! You do so much from providing care and support to fundraising, cheering and everything in between. And we want all our volunteers to have the best experience with us and to feel safe, supported and valued in their role.

To support this, we've been working towards the Investing in Volunteers (IiV) award this year. And in the next few months we'll be independently assessed for the accreditation. You can find out more about IiV at [investinginvolunteers.org.uk/about/benefits](https://investinginvolunteers.org.uk/about/benefits)

See page 2 for more info about our progress and the upcoming assessment.



# News and events

## Investing in our volunteers *continued*

So far this year we've made some great improvements including:

- introducing Online Recruitment, and new resources to help with recruitment
- updating key policies and working with volunteers on guidance for our policies
- new online training for Coordinating team members (see page 6)
- improving how we say thank you, including relaunching Shining Stars
- introducing a new exit process and survey for volunteers who leave us

### How we'll be assessed

Our independent liV assessor has sent out invitations to a cross-section of our volunteers and staff this month, inviting them to feedback about their experience. All their feedback and views will be used to assess whether we achieve the award.

If possible, the assessor will meet with people face-to-face, and over the phone. These conversations will take place in late October to early November. There'll also be a questionnaire so those of you who aren't invited to have a conversation with our assessor can share your thoughts too.

We don't know who'll be asked to take part in the assessment – it could be you! – but it's not a test. The assessor wants to get a full picture of how we work with and support our volunteers. It's not our volunteers who are being assessed!



**Audience:** All



**Action:** Share



**Contact:** Julie McWilliam, Investing in Volunteers Programme Manager  
[julie.mcwilliam@mssociety.org.uk](mailto:julie.mcwilliam@mssociety.org.uk)

## Ocrelizumab rejected for primary progressive MS

The National Institute of Health and Care Excellence (NICE), who approve drugs to be available on the NHS in England and Wales, has rejected the use of ocrelizumab for people living with early primary progressive MS.

Ocrelizumab is a drug that, since early 2018, has a Europe-wide license to treat relapsing MS and early primary progressive MS.

However, NICE have now rejected the use of ocrelizumab for early primary progressive MS. This is because the cost of the drug is deemed too high for the benefits it can provide.

This is incredibly disappointing news for the MS community, especially as there are no disease modifying treatments for primary progressive MS available on the NHS.

But this is not the end. We're calling for the manufacturer Roche, NICE and NHS England to put people with MS first and agree a deal to make ocrelizumab available at a price the NHS can afford.

We'll be in discussion with all those involved in the decision and have launched a petition calling for people with primary progressive MS to be put first.

You can find out more on our website at [mssociety.org.uk/ocrelizumabnews](https://mssociety.org.uk/ocrelizumabnews)

And please sign and share the petition with your members: [mssociety.org.uk/speakupforms](https://mssociety.org.uk/speakupforms)



**Audience:** All



**Action:** Share and sign the petition



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



# News and events

## Growing our community

We want to ensure that we're providing the best possible support for people living with MS. Our MS community is hugely diverse. Together we campaign for change, provide support and information, and drive forward progress in research. And to do this we need to be as inclusive and relevant to as many people in the MS community as possible.

### Reviewing our membership model

We're currently a membership organisation but, with our aim of growing the community in mind, we want to review this model.

A lot's changed since the MS Society was founded over 60 years ago. Today, people connect with us and support us in lots of different ways – through our website, social media, events, services and much more.

We know that, sometimes, non-members who support us can feel excluded, or worse, are excluded – whether due to the cost or process of joining as a member. We want to ensure that we're accessible to all, as well as remaining relevant and current.

Members are invited to vote on a resolution to give us permission to explore options of a new model and this will be discussed at our AGM on 22 September. If passed, the review will take in to consideration how we protect the membership fee income of our local groups.

If you're a member and eligible to vote at the AGM, you'll have received an AGM booklet with your copy of MS Matters with more information and outlining how to vote.



**Audience:** All



**Action:** Note



**Contact:** Supporter Care

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

## Stoptober is coming...

This year we're getting behind Stoptober to support people with MS who smoke and want to give up.

The evidence is clearer than ever: smoking can make MS worse. It can lead to bigger lesions and more relapses, and can speed up disability progression. We want to support people with MS – because we know how hard it can be to give up smoking.

### What is Stoptober?

Stoptober is a 28 day stop smoking challenge that encourages and supports smokers towards quitting for good. It's based on the insight that by stopping smoking for 28 days, you're five times more likely to be able to quit for good. Stoptober kicks off on 1 October – our MS community will be coming together to provide support and information for people with MS who want to quit.

There'll be space on our forum for people with MS to share experiences, and support each other. And we'll be sharing top tips and support on our social media channels and signposting to helpful resources online. You can find out more about Stoptober at [nhs.uk/Stoptober](https://nhs.uk/Stoptober)

Please share with your members and anyone you know who may want support to give up smoking.



**Audience:** All



**Action:** Share



**Contact:** Campaigns team

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



# News and events

## Cannabis for medicinal use confirmed!

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

This July, exactly a year after we started campaigning, the Government announced that they will make cannabis for medicinal use available by prescription in the UK. Plans are to reschedule cannabis-derived medicinal products by this autumn, making them legally available.

This is amazing news, and the MS community played an important part in calling for this change.

Evidence shows cannabis for medicinal use can work for some people to relieve pain and muscle spasms in MS. While there are NHS treatments for pain and spasms, these don't work for everyone. And Sativex, a cannabis spray, is only available on the NHS in Wales. This means legalising cannabis for medicinal use could help thousands of people with MS who haven't been able to find relief for their pain and muscle spasms.

It's still unclear what the system will look like and when cannabis will actually be available for those who could benefit. Together, we'll continue speaking up on this until people with MS who could benefit have access to this vital treatment.

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

## Scrap PIP 20 metre rule




In June we launched our petition to scrap the PIP 20 metre rule, and so far thousands of you have joined the campaign.

People with MS are losing access to the support they need to live independent lives because of the 20 metre rule. Personal Independence Payment (PIP) is a benefit that's meant to help people with MS. But the 20 metre rule means they're not getting the support they need. That's why we're campaigning for change.

The campaign got off to an amazing start. 40 MPs came to our launch event in Parliament, and in just 20 days over 20,000 people signed the petition.

We'll be handing the petition into the Department for Work and Pensions in mid-October. The more people who add their voices to the campaign, the stronger our call will be. If you'd like to sign or share the petition, you can do this at [mssociety.org.uk/scrapPIP20m](https://mssociety.org.uk/scrapPIP20m)

To help build pressure on the Government, we're also looking for people to meet their MP. If you're interested in meeting your MP or inviting them to your group, please let the Campaigns team know.

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



# News and events

## A Teamspirit make-over!

Your Teamspirit is having a little make over in time for the next edition in November.

Teamspirit has been around for a long time (over 10 years), and in that time the needs of our groups and volunteers have changed, and the MS Society has evolved. We want Teamspirit to be informative, clear and support you to run your groups.

### So, what's Teamspirit for?

- To provide **key information and support for Coordinating teams** to help run groups efficiently, and in compliance with policies and processes
- To **support volunteers**
- To keep you **informed about the MS Society**; key progress and the difference we all make together
- To provide content for your **group newsletters** to share with your members

### What are we changing?

To meet these needs and make Teamspirit as accessible and informative as possible we're going to restructure the layout and look of the publication. The content you're receiving will largely stay the same, but it'll be clearer.

Look out for this new look edition in November... we'll be asking you what you think and continuing to make improvements. After all, this is your publication and we want it to work best for you!

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




## Autumn Volunteer Forums

Our Autumn 2018 Volunteer Forums are almost here!



These forums are an enjoyable way for local group volunteers to come together for peer support, learning and sharing. As well as networking and to hear about, and get involved with, national work that may affect or be of interest to your groups.

All volunteers, and potential volunteers, in local groups are invited to attend. Details will be sent shortly about when and where local forums will be held, as well as how to book a free ticket to attend. Do also keep an eye on the Volunteer website events page at [volunteers.mssociety.org.uk/events](https://volunteers.mssociety.org.uk/events) as the forum dates will be added on there as well.

 **Audience:** All  
 **Action:** Share, book your place!  
 **Contact:** Services and Support Admin team  
[ssadminhelpdesk@mssociety.org.uk](mailto:ssadminhelpdesk@mssociety.org.uk)



# News and events

## 'Organising your Coordinating team' online training

We had fantastic feedback from volunteers who joined our previous online training sessions for Coordinating teams. Lots of you said you enjoyed connecting with people you wouldn't usually meet and loved being able to join in without having to go out!

We're currently upgrading MS Society email (see page 7), so we're focusing our next session on how MS Society email and our other tools support your Coordinating team to work together and achieve our goals.

By joining a session, you'll be able to:




- meet other Coordinating team members
- share your ideas and experiences and hear from other groups
- find out about the tools and resources available to support you

Online training is open to anyone who's currently in a Coordinating team, or thinking about joining one.

We're running morning, afternoon and evening sessions – we hope you'll find a time that suits you and join us:

- Tuesday 13 November, 11.15 - 12.30
- Thursday 22 November, 19.00 - 20.15
- Friday 30 November, 14.00 - 15.15

To find out more about how online training works and book your place, visit [volunteers.mssociety.org.uk/events](https://volunteers.mssociety.org.uk/events) or contact our Volunteering team.

 **Audience:** All  
 **Action:** Share  
 **Contact:** Volunteering team  
[volunteertraining@mssociety.org.uk](mailto:volunteertraining@mssociety.org.uk)




## GDPR eLearning is live!

All volunteers in roles that need to complete the GDPR eLearning have now been emailed a username and link to complete it.

Thank you to everyone who's already completed it. If you haven't yet been able to do the course, here's a gentle reminder.

The course takes up to 30 minutes to complete and ends with a short quiz. Unfortunately, the course is not accessible from a mobile but a distance learning pack is available

If you'd like to complete the training and haven't been emailed with details or have any questions, please get in touch.

 **Audience:** All  
 **Action:** Note  
 **Contact:** Volunteering team  
[volunteertraining@mssociety.org.uk](mailto:volunteertraining@mssociety.org.uk)

## Tell us about your induction




We want all new volunteers to know what to do and who can help, right from the start.

Please tell us about your experience starting a new role with us or supporting another volunteer to do so by completing this survey

<https://www.surveygizmo.eu/s3/90095131/Tell-us-about-Welcome-and-Induction>

The survey will close on 15 October.

The information collected will help us to make sure that we're offering the best possible support and resources to all volunteers during their induction with us.

 **Audience:** All  
 **Action:** Share, act – complete the survey  
 **Contact:** Volunteering team  
[volunteertraining@mssociety.org.uk](mailto:volunteertraining@mssociety.org.uk)



# News and events

## Upgrade on MS Society email accounts

Most of you are now using MS Society email for your groups. With this most recent upgrade, you'll get:




- mobile access to emails, documents and calendar
- Group shared document storage and calendar

As well as these two key improvements, you'll have individual accounts which link to the shared group or support account. This is important for volunteers who communicate on behalf of your group so we can ensure data is kept as secure as possible. It helps us all have more peace of mind and limit risk of data breaches.

We'll be providing information on the upgrade at the Autumn forums (see page 5), as well as during the next 'Organising your Coordinating team' online training sessions (see page 6).

In the meantime, you can already sign up to take advantage of the benefits of the new system – contact the Volunteering team if you'd like to know more.

You can also find out more at: [volunteers.mssociety.org.uk/MS-Society-email](https://volunteers.mssociety.org.uk/MS-Society-email)

 **Audience:** All  
 **Action:** Share, get involved!  
 **Contact:** Volunteering team  
[volunteertraining@mssociety.org.uk](mailto:volunteertraining@mssociety.org.uk)



## Resolving volunteer issues – new resources

Our Resolving Volunteer Issues policy helps to resolve issues quickly, fairly and in a transparent way.

Earlier this year, we consulted volunteers and staff on how to improve how we resolve volunteering issues. Since then, we've been working to update the policy and create resources to support you if you ever need to resolve an issue.

The resources include guidance to support someone raising an issue and someone who's involved in an issue, flowcharts to make the process more clear, and a note taking template. Visit <https://volunteers.mssociety.org.uk/Resolving-volunteer-issues> to find these resources.

You can also find an updated version of the policy at [volunteers.mssociety.org.uk/resources/RVI](https://volunteers.mssociety.org.uk/resources/RVI)

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

## Want to share your group's good news?

Send your story ideas to us at [teamspirit@mssociety.org.uk](mailto:teamspirit@mssociety.org.uk) and we'll be in touch!



# News and events

## Newspaper Licensing regulations

Like lots of other charities and organisations, we have to pay money each year to a company called the Newspaper Licensing Agency (NLA).

The NLA exists to copyright anything that's created by newspapers, and covers thousands of printed and online titles. Being a member means we can share any media coverage we've achieved, or anything else that's relevant to the MS Society or MS, with staff. Unfortunately, it's expensive and the licence only covers staff and not volunteers.

We'd ask that you don't photocopy any newspaper coverage you see or share with other volunteers on email as it could put us at risk of a big fine. We understand this is a bit of a pain but the regulations are strict.

If you have any questions about this – or any other work done by the press office – please don't hesitate to contact us on the details below.



**Audience:** All



**Action:** Note



**Contact:** Press Office

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

## Web to Print charges

Web to Print launched in 2016, with each group having a starting promotional budget of £150 to kick off the new resource.

Some of you didn't spend this initial budget, and others wanted to spend more. Orders through Web to Print will now be paid for by individual Coordinating teams – for you to spend as little or as much as you wish on personalised printed merchandise.

Please note, producing PDFs for printing locally will still be free.

### How will the Web to Print charging process work?

For printing costs incurred this year, up until June 2018, the charges will be taken directly from your group bank account in November 2018. For costs incurred from July to December 2018 the charges will come out of your group account in May 2019.

This charging will be the same year on year, with charges being taken in November and May for the previous six month period.

You'll be able to view these transactions through Online Accounting. And we'll be sending individual emails to Group Coordinators and Finance Volunteers with the specific amount, if applicable.

If you have any queries about the charging process, please contact your local LNO, or Supporter Care.



**Audience:** All



**Action:** Note



**Contact:** Brand and Marketing team

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





# News and events

## Information events

We're really excited to let you know about the upcoming information events happening this year. Don't miss out on an event near you!

### Research Awareness talks

A member of our Research team will give an informative and inspiring talk about the research we fund and a wide range of advances in MS research such as:

- stem cell therapy
- exercise and fatigue management
- clinical trial news

### Upcoming Research Awareness talks:

- Stratford-upon-Avon – 6 October 2018  
[mssociety.org.uk/care-and-support/local-support/research-awareness-talk---stratford-upon-avon](https://mssociety.org.uk/care-and-support/local-support/research-awareness-talk---stratford-upon-avon)
- Bedford – 18 October 2018  
[mssociety.org.uk/care-and-support/local-support/research-awareness-talk-bedford](https://mssociety.org.uk/care-and-support/local-support/research-awareness-talk-bedford)

### Living with MS events

At our Living with MS days you'll have the opportunity to:

- Take part in interactive workshops on topics such as exercise, benefits and symptom management
- Get up to date information from MS Society staff and professionals
- Visit relevant exhibitors including the MS Society's information stand
- Meet others affected by MS

### Upcoming Living with MS events:

- Newport – 20 October 2018  
(more information on page 22)  
[mssociety.org.uk/care-and-support/local-support/living-with-ms-newport](https://mssociety.org.uk/care-and-support/local-support/living-with-ms-newport)
- Coventry – 17 November 2018  
[mssociety.org.uk/care-and-support/local-support/living-with-ms-coventry](https://mssociety.org.uk/care-and-support/local-support/living-with-ms-coventry)

Our events are free and include refreshments. Please help spread the word with your members!



**Audience:** All



**Action:** Share



**Contact:** Conference and Events team  
[conferenceadmin@mssociety.org.uk](mailto:conferenceadmin@mssociety.org.uk)  
020 8438 0891



# Info and resources

## New resources

### Advanced MS handbook

Available now from the online shop or to download from our website is 'Advanced MS: a carers handbook'. This is the last in our series of three publications for family, friends and carers:

**For family and friends** (BK20 2016) – for people new to MS, who've recently found out someone they're close to has MS.

**Supporting someone with MS** (BK36 2017) – a guide for partners and family carers of people with MS but not severely affected.

**Advanced MS – a carers handbook** (BK37 2018) – a more in-depth guide for those facing the challenges of caring for someone at this stage of MS.

### BMA Patient Information Awards 2018

Three MS Society resources are shortlisted for the British Medical Association's awards for the best information for patients. Already judged 'highly commended' by the BMA, in the running for top prize in their categories are:

- our carer's booklet 'Supporting someone with MS'
- the 'Moving more with MS' booklet and exercise DVD
- videos filmed at our Belfast centre featuring exercises to relieve common symptoms

The ceremony is taking place on 25 September. People with MS who feature in these resources will be attending with our Information Resources team.

## Updated resources

### 'Talking about treatments' checklist

Our pocket-sized checklist leaflet 'Talking about treatments' from 2015 has been updated and given a make-over. It has tips for discussing disease modifying therapies (DMTs) during an appointment with a neurologist. Find it at [mssociety.org.uk/about-ms/treatments-and-therapies/our-treatment-stories](https://mssociety.org.uk/about-ms/treatments-and-therapies/our-treatment-stories)

### 'Pain'

Essential 17 'Pain and sensory symptoms' has been withdrawn and replaced by 'Pain and unpleasant sensations in MS'. Updated and in the new brand, it has more about the emotional side of managing pain. It's available to download or order using the code BK29.

### 'MS and your eyes'

Essential 5 'Vision and MS' has also been withdrawn. Taking its place is 'MS and your eyes' (code BK26). This booklet is also available in large print.

### DMT booklet

This remains a digital-only publication until NICE decide on ocrelizumab for progressive MS (expected in September), after which it will be available in print. 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)

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



**Audience:** All



**Action:** Share



**Contact:** Information team

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

020 8438 0799



# Research

## Requests to help study recruitment

We know that many of our local groups get asked to support recruitment for studies or trials, and it may be difficult to know when and what you should support. There are actually strict rules governing this for medical research, so if you're approached you can discuss and consider the following to help decide if your group should support a request.

### Can the researcher produce evidence of ethics approval?

Ethical approval is the oversight hospitals and universities have over every project. It will usually be in a letter format, outlining the ethics and how the project can recruit participants. Please ask to see evidence of this, and if they don't have it, decline their request. This doesn't apply to simple surveys, which aren't recruiting people.

### Is it market research?

Market research is usually a commercial company carrying out research in to a product. We don't support recruitment for market research so please turn these requests down.

### Are you interested in the research?

Our groups are under no obligation to host researchers, but you can do if you're interested. We encourage researchers to involve people with MS in developing their projects and if this isn't obvious in their request then it may be worth asking about this. Unfortunately studies vary in quality and student projects in particular may be more focused on delivering a dissertation than achieving meaningful impact for people with MS. Speak to the researcher and check that it's something of real interest to you and your group.

### Are you and the researcher taking a balanced view?

If you're helping a study or trial this must be on the understanding that the MS Society, including our groups, is not endorsing the study or advocating for or against participation. As well as this, visiting researchers shouldn't directly ask individuals to participate in their study, but can provide information on how people can join as part of any presentation explaining their work.

If you have any questions please contact your LNO for further support.



**Audience:** All



**Action:** Share



**Contact:** Your LNO



# Fundraising

## Update re Give As You Live

Many groups are now signing up to use Give As You Live (GAYL) as an easy way to raise funds – which is great!

Leaflets to promote this super way of raising funds for your group through online shopping are now available via the MS Shop. Item number MSSF-GAYLPCK50-18.

All income the MS Society receives from Give As You Live is potentially subject to VAT at 20%. This is because Give As You Live are part of a commercial company who derive a benefit from being linked to the MS Society. To avoid paying over the VAT, 10% of the income must go through the MS Society's trading company with the remaining 90% going to groups. As fairly small sums are involved, it will not be economic to transfer the Trading company monies back to the group that this donation was generated through. The changes required to make this happen will be carried out centrally so there is no need for the group to do anything. We will make this change from 1 October.

So get your group, and supporters you are in touch with, signed up to this very easy way of raising funds. Further guidance is on the volunteer website.



**Audience:** All



**Action:** Note



**Contact:** Your Area Fundraiser

## Direct Marketing update

### Christmas Cards

Christmas has landed already with the MS Society Christmas cards on sale through Cards for Good Causes. There are 10 different designs, including two special London designs, all being sold nationwide and online to raise an expected £80,000. Check out the designs and find your local store at [cardsforcharity.co.uk/our-charities/ms-society.html](https://cardsforcharity.co.uk/our-charities/ms-society.html)

### September Appeal

Our September Appeal arrived with 35,000 supporters last weekend focussing on the importance of supporting young scientists in order to advance MS research. A reminder mailing will be going out to supporters in the next few weeks, and we're hoping to raise almost £130,000.

### Christmas Raffle

The Christmas Raffle opens on 8 October, and we're hoping to raise over £145,000! The closing date for postal entries is Friday 14 December, and you can enter online at [raffleentry.org.uk/mssociety](https://raffleentry.org.uk/mssociety) until Thursday 20 December 2018. With the chance to win a top prize of £5,000, get your entries in soon!



**Audience:** All



**Action:** Share



**Contact:** Supporter Care

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

0300 500 8084



# Finance

## Agreed Upon Procedure (AUP) report

### What is an AUP report?

It is a report covering specific accounting procedures which are checked by an independent qualified accountant. For the MS Society it was introduced in 2003 and around 20 to 25 MS Society groups have to get this report completed each year.

### Why do some groups have to complete the AUP report?




The AUP report is to give our external auditors additional assurance on the accounting records held by groups. The AUP report is therefore sent to the larger groups, those who undertake certain activities and those groups where there is perceived to be greater risk. The same groups are not always selected.

### How will your group be notified if an AUP is required?

We will notify you in the Year-end 2018 Finance email that will be sent to your group e-mail address, on 24 September. We'll also enclose guidance on what to do next i.e. how to source the services of a local independent qualified accountant etc.




### Does my group have to pay any fees for getting the AUP signed off?

Yes. If your group is selected to submit an AUP report as part of the MS Society's year-end audit requirements, the group will be responsible for paying the fees for it.

 **Audience:** Finance Volunteers  
 **Action:** Note  
 **Contact:** Finance team  
[financesupport@mssociety.org.uk](mailto:financesupport@mssociety.org.uk)




## BACS transfer replacing cheque payments

Payments made via MS National Centre will no longer be made by cheque. If you submit a claim for reimbursement of expenses, you'll need to provide our Accounts Payable department with your current bank account number and sort code, so that a payment by BACS transfer can be made to you.

 **Audience:** All  
 **Action:** Note  
 **Contact:** Accounts Payable  
[accountspayable@mssociety.org.uk](mailto:accountspayable@mssociety.org.uk)

## 2018 Year End preparation

As we speed through another year we would like to make you aware of the Finance 2018 Year End email. This will be sent out to all groups on 24 September, so please look out for this in your group MSS email account. The email will provide you with all of the information on the Year End process, and also give you some useful tips on how to plan ahead. If you don't receive this email, please contact the Finance team as soon as possible.

 **Audience:** All  
 **Action:** Note  
 **Contact:** Finance team  
[financesupport@mssociety.org.uk](mailto:financesupport@mssociety.org.uk)  
0131 335 4078 / 0208 438 0875



# Finance

## Finance visits

Finance visits are carried out by a member of the Finance team to check a group's internal financial controls. It's not an audit and not to be confused with the AUP report.

### What's the purpose of a finance visit?

Trustees have ultimate responsibility for all group income, expenditure and reserves held. The finance visits give trustees assurance that groups are complying with the MS Society's financial rules and have adequate internal controls in place. Groups who receive a visit will receive recommendations on any areas where controls are not adequate or rules not being followed. A report goes to each Audit, Risk and Finance Committee meeting which outlines all the finance visits undertaken (Committee includes trustees and reports to the Board).

### Why might a group receive a finance visit?

Your group may be selected due to one or more of the following reasons:

- Your group has a property (i.e. shop, Day Centre etc.) and or large fleet of vehicles
- Your group has a high level of reserves
- Your group is unable to sustain current activities for financial reasons
- Your group is not complying with the MS Society financial rules. This includes not keeping Online Accounting up to date on a regular basis (at least monthly)
- Your group did not submit year end information within the given deadlines
- Suspicion/allegation of fraud within your group, or misuse of MS Society funds
- Two groups each year, from anywhere in the UK, selected entirely at random

### How and when is a finance visit conducted?

Ideally these would be done at a group Coordinating team meeting, as all members of the Coordinating team need to be present during the visit, as it's their responsibility to ensure sufficient financial controls are in place.

A finance visit usually involves a review of the following:

- Accounting records.
- The group's most recently completed Internal Financial Controls Checklist.
- Minutes from Coordinating team meetings.
- Income and expenditure forecast/budget.
- Internal group processes i.e. how is expenditure authorised by the group? How often are group finances reviewed? Is each team member aware of their responsibility to safeguard the MS Society's assets? Etc.
- Address specific concerns raised by MSNC and/or Coordinating team.



**Audience:** Finance Volunteers



**Action:** Note



**Contact:** Finance team

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



# Finance

## Meet the Legacies team

Meet our friendly Legacies team, based at MS National Centre!  
We thought it useful to introduce ourselves and let you all know how we can assist you.

**Fabian**, our Legacy Case Manager, deals with all legacy administration, meaning he ensures every gift left to us by our kind supporters in their Wills is correctly processed and acknowledged. If any legacy correspondence or cheques are received directly to a group, you need to make sure that this is forwarded directly to Fabian. Fabian can help with all questions relating to legacies left to your groups.



**Adam**, Legacy and In Memory Manager, deals with all legacy promotions, meaning he helps anyone wishing to leave the MS Society a gift in their Will. We promote legacies through direct mailings and legacy events. We also have a comprehensive information pack, including all you need to know about leaving a gift, as well as information about our Will-making services. Adam can help with all questions relating to Will-making and leaving a gift, and advise on the clause wording for leaving legacies to local groups.



**Audience:** All



**Action:** Note



**Contact:** Adam and Fabian

[adam.west@mssociety.org.uk](mailto:adam.west@mssociety.org.uk)

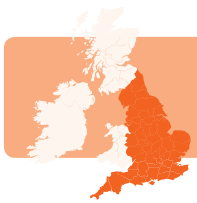
020 8827 0374

[fabian.ouchterlony@mssociety.org.uk](mailto:fabian.ouchterlony@mssociety.org.uk)

020 8438 0763

## Online Accounting web link

Along with the recent Online Accounting security update, the web link has also been updated. The new link is: <https://branchaccount.mssociety.org.uk/OpenPages/Login.aspx>



## For England

### Super swimmers raise funds in Isle of Wight!

Group volunteers, Jennie Harrod, Kathy Lakin and Lisa Addison (pictured below) take on a swimming challenge to support people living with MS.



In May, the annual Swimathon in Sandown saw four teams of up to six people swimming in relay to try to win awards for the most laps swum. Each swim lasted 55 minutes. The pool was full of swimmers from midday until the last teams entered the pool at 5pm.

This year, our Isle of Wight group was chosen as one of the three local charities to receive sponsorship from participants. And not only that, the group support a Saturday Swimming Club for people with disabilities, providing funding for people with MS to attend the club. Two teams from the club entered the competition, including group volunteers Lisa, Jennie and Kathy, all of whom have MS themselves.

The two teams managed to swim the equivalent of around 3 miles in their 55 minutes – not enough to win a cup but an incredible effort for seven people with various disabilities!

A big shout out has to go to Kathy in particular – who swam around 30 lengths, having never swum a full length six weeks beforehand. An astounding achievement!

A couple of months later our three volunteers attended the presentation of the awards and cheques. The Isle of Wight group were presented with a cheque for £990 – thanks to the efforts of every swimmer who took part on the day!

#### **Saturday Swimming Club**

The Club is a great success, making a big difference to people in the local area.

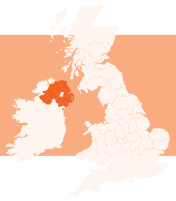
Jennie Harrod said, *“To see Kathy’s confidence in the water grow makes the club worthwhile, all three ladies cannot praise the activity highly enough and look forward to the weekly sessions in the pool – more members are always welcome.”*

Members pay an annual £15 ASA membership and insurance and then people with MS attend for free, with carers paying just 50p per session thanks to the IoW group’s funding!

 **Audience:** England

 **Action:** Share





# For Northern Ireland

## Message from new Director for Northern Ireland

We're delighted to introduce David Galloway, who has been appointed as our new Director for MS Society Northern Ireland. David will take up post this month replacing outgoing Director Patricia Gordon.

A message from David:

*"I am delighted to be joining the MS Society to lead the team in Northern Ireland.*

*I'm coming to the MS Society from the Royal National Institute of Blind People where I was Northern Ireland Director for five years and most recently have held a UK-wide role. Before that I worked at the Department of Health in Belfast where among other things I was involved in decision making about investment in disease modifying therapies and MS services.*

*On a personal note, my father-in-law had MS and that experience is still felt within the family. That was one reason why my attention was drawn to the opportunity to join the MS Society but I was mainly attracted by the Northern Ireland Director role because this charity is so clearly passionate about helping people affected by MS and improving care and treatment services. Looking in from the outside, the energy and commitment of everyone involved in the work of the MS Society stands out.*

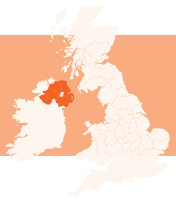
*Of course, I know it'll take a while to get to know everyone but I plan to get out around the country and meet people in our local groups over the coming weeks. I'm looking forward to that and I will be listening intently to what you have to say."*



**Audience:** Northern Ireland



**Action:** Note






## For Northern Ireland

### Update on recall announcement of neurology review

The recall of 2,500 neurology patients by the Belfast Trust has been a worrying time for many people affected by MS and their families. While affected patients have now received a consultant led assessment, for some there remains additional uncertainty and further appointments will be necessary. Both staff and people affected by MS continue to work on this important issue with the Belfast Trust and the Department of Health. This includes the recall itself, the circumstances which led up to it as well as the future of neurology services in Northern Ireland.

The Health and Social Care Board has recently announced a stakeholder workshop bringing together Trust staff, MS professionals, the Department of Health and charities. We'll attend and ensure the views and experiences of people affected by MS are heard. Additionally the Department of Health has also announced a departmental review of Neurology which will shape the future of the service. This will begin in September and again we'll play a full and active role in ensuring the views of our community are central within this review.

If you have an experience on the recall you'd like to share or an issue you would like us to raise on the review of neurology please get in touch.

 **Audience:** Northern Ireland  
 **Action:** Share  
 **Contact:** Northern Ireland reception  
[nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk)  
02890 802802

### Update on the co-production of our Big Lottery bid




The MS Society NI team are currently putting together a bid for the Big Lottery Fund to develop services to support and improve the emotional health and wellbeing of people living with a diagnosis of MS in the Mid and East Antrim council area. This bid is being co-produced with people affected by MS.

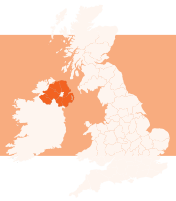
After advertising across social media we were able to bring together existing volunteers from our local groups and recruit people living with MS to co-production sessions.

We want to ensure everyone's voice is heard and have developed three co-production models for people to have their say on the service being developed; these options include attending co-production meetings, having a telephone conversation to submit views or by joining a virtual meeting via Zoom.

The co-production meetings have been going extremely well and we've received fantastic feedback and new ideas. Many participants said they were excited to be part the project and proud to be able to design a service for people living with MS in their local community. Co-production meetings are ongoing in planning the next stage of the bid.

If you'd like further information please contact Paula on the details below.

 **Audience:** Northern Ireland  
 **Action:** Share  
 **Contact:** Paula Mclarnon, LNO (NI – North)  
[paula.mclarnon@mssociety.org.uk](mailto:paula.mclarnon@mssociety.org.uk)






# For Northern Ireland

## IT Matters sessions

Our Big Lottery 'Awards for All' funded programme 'IT Matters' continues...

The six-week programme has run in Omagh and Belfast. The next set of sessions will be running in the Northern Trust area. They'll take place in Ballymena starting in October. If you'd like to take part or want further information please contact Paula.




-  **Audience:** Northern Ireland
-  **Action:** Share
-  **Contact:** Paula Mclarnon, LNO (NI – North)  
[paula.mclarnon@mssociety.org.uk](mailto:paula.mclarnon@mssociety.org.uk)

## Information on Access NI checks

In Northern Ireland, people engaging in regulated activity with children and vulnerable adults are required to complete an Access NI check. We have active processes in place to assist and administer this system.

Usually it's volunteer and therapist roles at the MS Society which require Access NI clearance. Application forms and a Pin Notification and Identification forms are issued from the Resource Centre for completion. These need to be returned to the MS Society for the attention of Ann Wilson. We require three forms of identification to be submitted with the forms. A list of accepted forms of ID is noted on the Pin Notification form.

The Access NI check is free for volunteer roles and there is a charge of £38 for therapists charging for their services. Therapists' Access NI checks can't be processed until the fee is submitted to the MS Society. Checks are renewed every three years and we'll send renewal forms two months ahead of the existing check expiring and ask these are returned within the time period. If we don't receive the renewal forms prior to the previous Access NI expiry date, the volunteer/therapist will be permitted to continue in the volunteer/therapist role until the end of the expiry month.

-  **Audience:** Northern Ireland
-  **Action:** Note
-  **Contact:** Ann Wilson, Executive Administrator to Director of NI  
[ann.wilson@mssociety.org.uk](mailto:ann.wilson@mssociety.org.uk)



# For Scotland

## Ocrelizumab rejected for relapsing MS in Scotland

In July, we were disappointed to find out that ocrelizumab had been rejected for routine use on the NHS in Scotland for people with relapsing MS. In Scotland, the Scottish Medicines Consortium (SMC) determine whether treatments should be available. They decided that the cost of ocrelizumab was too expensive for the potential benefit, and that other treatments were more cost effective. Encouragingly, a resubmission has already been made by the pharmaceutical company to the SMC. We hope to get a new decision by the end of 2018.

The pharmaceutical company had also put in a submission for ocrelizumab to be a treatment on the NHS for people with early primary progressive MS. Unfortunately, this has been withdrawn and won't be going forward for assessment by the SMC at present.

We've been working to understand the reason behind the withdrawal of the primary progressive submission and find out about potential next steps. We want to make sure that everyone with MS has access to the right treatment at the right time.

### Update on Fampyra

Before the end of this year the SMC will make a decision about whether the symptom management treatment Fampridine (Fampyra) will be available on the NHS in Scotland. This treatment can help with walking speed. We'll be supporting the submission as it goes through the SMC.



**Audience:** Scotland



**Action:** Share, note



**Contact:** Scotland Campaigns team  
[scotlandcampaigns@mssociety.org.uk](mailto:scotlandcampaigns@mssociety.org.uk)  
0131 335 4050

## Focus groups on Scotland's new social security system

Over the autumn we'll be running a series of short focus groups with local groups across the country, include one online. We want to be able to give the Scottish Government concrete examples of how the new Social Security Agency should operate in the best interests of the people using it.

The new agency will deliver the disability benefits that are being devolved to Scotland, including Personal Independence Payment (PIP), Disability Living Allowance (DLA) and Carers Allowance.

So we want to hear your experiences, good or bad, of the current benefits system to help us shape the guidelines and regulations that staff will have to follow in the new system.

It will be a while before the new system is up and running. But we want to make sure that when it is, it works right from the start for people living with MS.

(Please note – as we reported in the May edition of Teamspirit, the Scottish Government have indicated they will pay a supplement to Carers Allowance from late summer 2018, while the Department of Work and Pensions (DWP) will pay the main Carer's Allowance. Once the new agency is established in Scotland it will pay all of Carers Allowance with the increase.)

Dates and venues for the focus groups are still to be confirmed, but more information will follow shortly. In the meantime, please email our Scotland Campaigns team if you have any questions.



**Audience:** Scotland



**Action:** Share



**Contact:** Scotland Campaigns team  
[scotlandcampaigns@mssociety.org.uk](mailto:scotlandcampaigns@mssociety.org.uk)  
0131 335 4050






## For Scotland

### Scotland fundraising team launch first overseas challenge

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 travel to Rovaniemi in Finland and spend three days trekking into the Arctic. This trek isn't for the faint hearted – participants will be pulling equipment in a pulk (a Nordic toboggan), battling the elements while trekking in sub-zero temperatures and sleeping in tents. It's a challenge of a lifetime! Do you know anyone who may want to take part? Email us to find out more.

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



## For Wales

### Living with MS event in Newport

We're excited that our popular Living with MS information day will be held at Coldra Court on Saturday 20 October.

You'll have the chance to hear up-to-date and relevant information from talks, workshops and exhibitors. The MS Society information stand will be there and will have lots of publications that you can take away with you.

The event will focus on health and wellbeing and you'll be able to choose from a selection of interactive workshops. The day will kick off with an informative update on MS research. This will include what research we're funding and exciting developments.

This is a great opportunity to meet other people affected by MS and get to know other people in the local area.

You don't have to commit to the whole day. Come for however long suits you. The event is free and includes refreshments.

We're really looking forward to seeing you there!

#### How to book

Online: [mssociety.org.uk/care-and-support/local-support/living-with-ms-newport](https://mssociety.org.uk/care-and-support/local-support/living-with-ms-newport)

Call: 020 8438 0891



**Audience:** Wales



**Action:** Share



**Contact:** Conference and Events team  
[conferenceadmin@mssociety.org.uk](mailto:conferenceadmin@mssociety.org.uk)  
020 8438 0891



*Exercise session at Living with MS event, Southampton 2017*



# Group contributions

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

## Group contributions 25/05/18 to 01/08/18

Group Name	Earmarked Description	Earmarked	Research	General
Ballymoney Group			£10,000.00	
Castledearg Group	Myelin Repair	£2,500.00		
Clacton & District Group	Myelin Repair	£1,000.00		
Havering Group (London Borough)			£1,500.00	
Havering Group (London Borough)	Helpline	£1,500.00		
Hillingdon Group	Myelin Repair	£5,000.00		
Hillingdon Group	Tissue Bank	£5,000.00		
Hillingdon Group	Stem Cell	£5,000.00		
Kyle Group	Edinburgh Centre for Translational Research	£2,000.00		
Lochaber Group			£500.00	
Melton & Rutland Group			£2,500.00	
Oxford & District Group			£5,000.00	
Stratford Upon Avon & District Group			£1,655.00	
Waltham Forest Group			£5,000.00	
Yeovil & Sherborne District Group	Myelin Repair	£1,500.00		
Yeovil & Sherborne District Group	Stem Cell	£1,500.00		
<b>Total</b>		<b>£25,000.00</b>	<b>£26,155.00</b>	



# Classifieds

## 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 2018 for both properties, please contact the Bexley & Dartford group on 0208 306 7050 or email [bexley@mssociety.org.uk](mailto:bexley@mssociety.org.uk).

## Holiday lodge

The North Norfolk group run a Holiday 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 hoist running into wet room.

The cost is from £300-£600 per week from Saturday to Saturday for 6 people, and includes all passes for Park. For Park amenities please visit [parkdean.com](http://parkdean.com)  
For availability ring Dave on 07793 414874 or email [dandm4sc@btinternet.com](mailto:dandm4sc@btinternet.com)

## 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.







# Teamspirit directory

## 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