MS Society

Stronger together

May 2021

Teamspirit

Contents

Introduction

Hello.

It's been over a year now since we produced our last issue of Teamspirit. Back in March 2020, few of us could have predicted the enormous amount of change that lay ahead. It's been an incredibly difficult time for so many of us. Lockdown restrictions have had a big impact on both our daily lives and our social and support networks.

As an organisation we've needed to respond quickly and significantly to the changing situation, and adapt the way that we work to make the best use of our resources with significantly reduced income. This has led to lots of changes which have been difficult for staff and volunteers alike. But, despite the challenges, together we've continued to be there for people living with MS, at a time they've needed it most.

Through all this change, I've been hugely heartened to see how our local groups have adapted and found new ways to support the MS community. Over 60% of our groups have continued to be active throughout the pandemic by moving services and social opportunities online, whilst continuing to provide telephone support and information about our national services. Some of our groups also joined forces to provide new opportunities for people who previously weren't able to attend activities in person to connect with others. This issue of Teamspirit includes a celebration of what was achieved across our group network, and may give you some ideas that your group could try, even after we emerge from lockdown.

As well as looking back over recent achievements, this issue will outline our process for reopening face-to-face activity. We know that some of you will be raring to get your activities going again, whereas others will feel more cautious or apprehensive about restarting face-to-face services. This is understandable, and we aim to strike a balance with a staggered restart so you can be confident that you have everything you need to keep your volunteers and service users safe. We also explain our new staff structure, and the support available to you and how to access it, as well as our organisational plans for the year ahead.

I'd personally like to say a huge thank you for your commitment to our work during this difficult time. Even if your group has been inactive during the pandemic, we value and appreciate your commitment to volunteering with us, and we hope that you'll feel able to resume your volunteering at a time that is right for you. And I'm very much looking forward to visiting groups soon so that I can thank many of you in person!

David Light
Head of Community Networks

Listening and improving

In 2019, we conducted a review of our support for volunteer groups. This resulted in a number of recommendations for improvements to the way we work. Although the pandemic has meant that some of these change projects have, unfortunately, been paused, we're still absolutely committed to working through these recommendations to ensure you have the support you need for your group to continue and thrive.

While the COVID situation has meant that we've needed to make significant cost savings, the changes to our staff structure (detailed on on pages 6 and 7) have been designed with the 2019 review recommendations in mind. This will ensure that we provide a more consistent level of support, with an emphasis on improved communication with volunteers.

Communication

One of the key areas that you thought we could improve was how we communicate with you as group volunteers. You told us that you're often overloaded with messaging from different departments which can be confusing. You told us that, while there's a lot of information on our Volunteer Website, it's text heavy and not always easy to find. And you said you didn't always feel that your concerns are listened to.

We've already acted on this feedback by introducing fortnightly Community Networks emails and establishing our monthly Volunteer Voice events. Volunteer Voice is an opportunity for volunteers to come and talk directly with our CEO, Nick Moberly, and other senior members of staff and trustees. These events are proving popular and are a great way for volunteers and staff to come together in positive and helpful discussion. You can find upcoming dates and details of how to join a session on the Volunteer Website.

Improving how we communicate and engage with you is a key priority for us this year, and for the first time we now have a small but dedicated Volunteer Engagement & Communications Team, who will be working to improve our regular communication channels. This will include a review of Teamspirit in collaboration with a number of volunteers, to help us ensure our groups have the support and information needed to be as effective as they can be. We'll keep you updated on the outcome of this review.

The team will also focus on simplifying our online information (on the Volunteer Website), and finding new and more interactive ways to support volunteers to learn and develop their skills. We'd also like to find ways for volunteers to connect with staff and each other through the use of social media and our online forums. We want to make it easier to share our stories and achievements to encourage each other, and to promote the work of our local groups much more effectively.

Systems and processes

You told us that our systems and processes work well but can be complicated and not built with people with MS in mind. We also heard that groups aren't involved enough in testing and deciding upon new systems, that rollout can feel rushed, and that sometimes there's not enough ongoing support.

We'll continue to improve and simplify our systems where possible, and, although it may take time, we're working towards bringing our online tools together in one place so that volunteers don't need to log in to multiple websites with numerous passwords.

We'll introduce a Community Networks Advisory Panel to help us improve our systems and processes alongside the volunteers who will be using them. To find out more about this, and how to get involved, please go to page 5.

Listening and improving

Spreading the load

You told us that you can feel over-burdened by bureaucracy, so we want to make things as simple and straightforward as we can. We're working on a self-assessment framework for groups. This will aim to bring all our compliance requirements together in one place so that groups are able to take ownership of their responsibilities in a simple and straightforward way.

We also want to support you to recruit and retain new volunteers. Our Volunteer Recruitment Officer will work alongside groups to advertise vacancies and will also be reviewing key roles to ensure they're manageable and realistic.

We want volunteering for the MS Society to be a fun and rewarding experience and volunteers are helping us to plan new ideas to achieve this.

We also recognise that our groups often feel under real pressure to provide a wide range of services and support in their community. Our new Regional and Community Development Officers will be on hand to make connections and support you to form partnerships and meet need more collaboratively. We also want to make our local groups feel more connected to the wider organisation, so you feel confident about referring local people to MS Society services that are delivered nationally.

Working in partnership with our group volunteers

We feel confident that the changes we're making will enable us to provide the high-quality support that our local groups need to continue and flourish. However, as a result of our reduced income, our resources are limited, and because our staff numbers have reduced, we won't be able to provide the bespoke support we did before.

For us to have the biggest possible impact for the MS community, it's important that we work together as one organisation to ensure we're providing joined-up and reliable support for people affected by MS. So, we need you, our volunteers, to work according to our policies and codes of conduct, and to keep us informed of any changes to your group personnel or the activities that you run. We're here and keen to support you as best we can. But we can only do so effectively if we have accurate information about you, your volunteer team and the activities your group is delivering.

Together we are stronger, together we have impact and together we can help improve the lives of those with MS.

Again, thank you all for your time and efforts to support your local MS community through such a challenging time.

We look forward to achieving great things with you in 2021 and to brighter times ahead.

Join our Community Networks Advisory Panel!

It's important to us that you have the tools and support you need to serve your MS communities, and that volunteering with us is an enjoyable and rewarding experience. We want to make sure that those systems and resources are designed in partnership with the volunteers that will use them, and that decisions affecting local groups are made by volunteers and staff working.

With this emphasis on collaboration in mind, we're launching a Community Networks Advisory Panel. This group will provide a forum for meaningful volunteer involvement and input to key decisions that affect the work of our groups.

As a member of the Community Networks Advisory Panel, you'll play a leading role in reviewing the strategic impact of our recent reorganisation (including the effectiveness of changes to group support), and will recommend to the Executive Group any necessary improvements. You'll also help to shape future changes that affect our local groups. So, you'll need to be a current group volunteer or national council volunteer to apply for this role.

We're looking for 10-15 volunteers from across the UK, in a variety of group roles, to form this Panel. Meetings (four per year) will be held online, with additional discussions taking place via email. Panel members will be expected to serve a minimum two-year term.

We're looking for people to bring their experience and knowledge of volunteering within the MS Society, as well as relevant experience from other aspects of their lives. If you have a positive approach, an open mind, a desire to contribute new ideas, and a willingness to listen to and consider the suggestions of others, then this could be the role for you!

If you're interested in being a Panel member, please apply using this online form: forms.office.com/r/WGtpUP6rgZ.

Community Networks

POLICY & PERFORMANCE MANAGER
Kim Yallop

QUALITY & SAFEGUARDING LEAD
Chris Evans

POLICY & PRACTICE OFFICER
Eva Isla

HEALTH & SAFETY OFFICER
Andy Grant

GRANTS COORDINATOR
Kerrie Trim

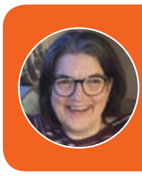
SYSTEMS & DATA OFFICER
Anne-Marie Lawrence

COMMUNITY NETWORKS ACCOUNTANT
Tina Akissennoh

POLICY & PERFORMANCE TEAM

Key aims:

- Clarify group policies and processes
- Improve the systems groups use
- Monitor and report on impact



REGIONAL DEVELOPMENT MANAGER
Abby Caskie

'IMPROVING QUALITY OF LIFE' PROJECT

PROJECT OFFICER
Mark Pritchard

ADMIN OFFICER
Mia Tamarin

REGIONAL DEVELOPMENT OFFICERS

ENGLAND
Samsam Abdullahi
Sheila Greenwood
Jeremy Harris
Gina Meyer
Gina Rutterford
Lyndsay Smith
Sally Snowball
Karen Tucker

COMMUNITY DEVELOPMENT OFFICERS

NORTHERN IRELAND
Susan Carey
Charlotte Shirley

WALES
Leila Middlehurst-Evans
Brian Watson

SCOTLAND
Tracey Harrison
Paula MacGillivray

REPORT TO COUNTRY DIRECTORS

REGIONAL/ COMMUNITY DEVELOPMENT TEAM

Key aims:

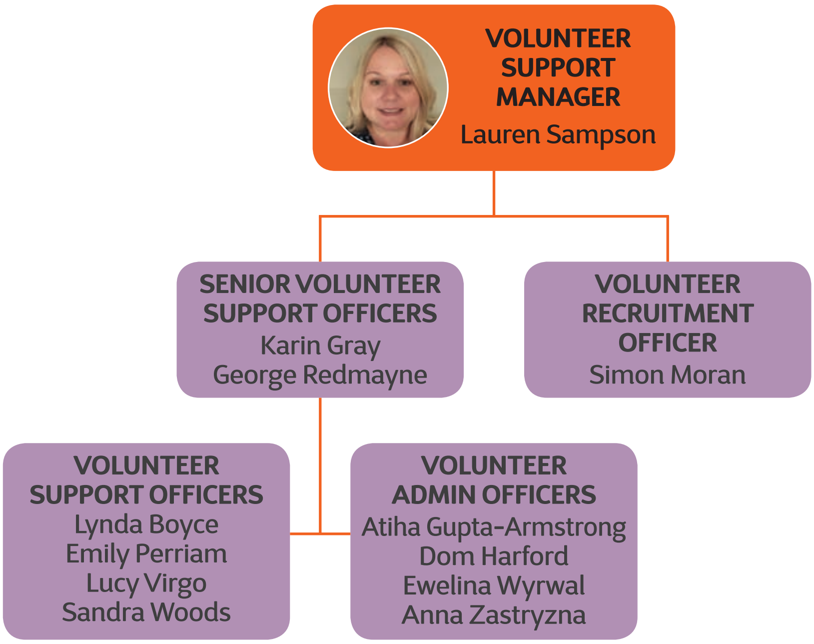
- Network in the community
- Support local group partnerships
- Carry out annual group check

HEAD OF COMMUNITY NETWORKS
David Light

VOLUNTEER SUPPORT TEAM

Key aims:

- Day-to-day group support
- Support volunteer recruitment
- Host online info sessions



VOLUNTEER SUPPORT MANAGER
Lauren Sampson

SENIOR VOLUNTEER SUPPORT OFFICERS
Karin Gray
George Redmayne

VOLUNTEER RECRUITMENT OFFICER
Simon Moran

VOLUNTEER SUPPORT OFFICERS
Lynda Boyce
Emily Perriam
Lucy Virgo
Sandra Woods

VOLUNTEER ADMIN OFFICERS
Atiha Gupta-Armstrong
Dom Harford
Ewelina Wyrwal
Anna Zastryzna

VOLUNTEER ENGAGEMENT & COMMUNICATION TEAM

Key aims:

- Produce regular comms to groups
- Create content for volunteer website
- Develop online info sessions

VOLUNTEER ENGAGEMENT & COMMUNICATION MANAGER
Emma Hodges

VOLUNTEER ENGAGEMENT & COMMUNICATION OFFICERS
Romi Rauber
Jo Webber

Restarting face-to-face services

Restarting face-to-face group services and activities

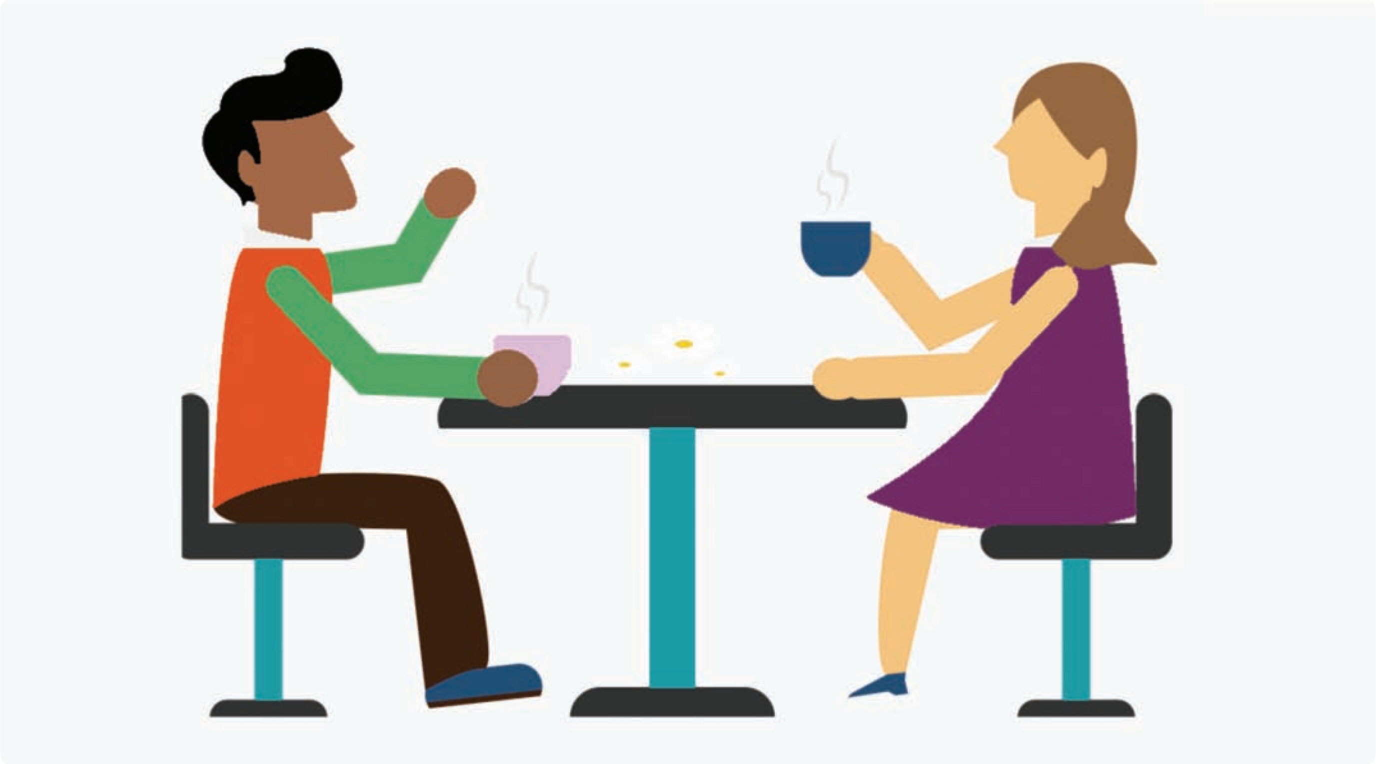
When we had to suspend all face-to-face group activity last year, many of our groups did a fantastic job of successfully moving their services online. Some services have, in fact, worked so well online that groups plan to continue running them this way long term. But we also know that some groups are looking forward to restarting services face to face, and restoring a bit of 'normality'.

We're taking a staggered approach to restarting, to reflect the gradual easing of lockdown in the different nations. It also helps us to ensure that new paperwork and processes are in place for restarting to happen in a COVID-safe way, and that we can provide support.

Opposite is our 'roadmap' of possible start dates for different types of face-to-face services. We hope to stick to these, but all plans and dates are subject to change depending on governmental announcements and COVID restrictions.

Visit our 'face-to-face restarting' page on the Volunteer Website here volunteers.mssociety.org.uk/news/2021/03/restarting-face-face-services for more information and details of the mandatory Zoom session(s) you'll need to attend to find out what your group needs to do. Or contact the Volunteer Support Team (0300 500 8084 #3, or volunteersupport@mssociety.org.uk).

But if your group would rather wait until later in the year to restart face-to-face services, that's absolutely fine. The most important thing is that our volunteers and service users feel safe and happy, so there's no pressure to restart.



Restarting face-to-face services

	ENGLAND	CYMRU	SCOTLAND	NORTHERN IRELAND
SLA 1-to-1 services These can also be provided in individuals' homes	12 April 19 April	12 April 19 April	26 April 26 April*	12 April 19 April
Up to 6 people in England **Up to 6 people in Scotland** **Up to 15 people in Cymru** **Numbers in NI reviewed in May** **(Exercise = venue size)** SLA group services Group events / meetings in managed venues	17 May 17 May	3May 17 May	17 May 17 May	24 May 24 May
Unlimited number of participants SLA group services Group events / meetings in managed venues	21 June 21 June	TBA ?	TBA ?	TBA ?

Group requirements for services with an SLA:

- New COVID-safe SLA in place
- If an unmanaged venue is being used, this **must** be hired by service provider
- SLA signed and uploaded to Portal

Meetings in managed venues and social activities:

- COVID-safe guidance document in place
- Activity logged to Portal
- Guidance process currently being developed

CLICK HERE FOR DEFINITIONS OF 'MANAGED' AND 'UNMANAGED' VENUES

Activities that will initially remain on hold:
Coach trips; Street collections
Meetings in unmanaged venues; Store collections
Stalls and activities; Meetings in members' homes
Low level physical activities (organised by the groups – wheel and walks)

Announcements expected
Cymru – next review TBC
Scotland – from 17 May, plan to move to Level 2 across the nation
Northern Ireland – Review date to be announced in May (prior to 24 May)
England – Dates reviewed after each preceding reopening date
Isle of Man – Circuit-break lockdown to be reviewed 6 April
Guernsey – Lockdown ended 22 March

Key: Government restart date MSS will support date (*Scotland subject to your tier level) TBA – to be announced

Grants update

Although the national grants service was paused in 2020, many groups continue to receive, assess and award grant applications at a local level. We've now updated our guidance for local groups who assess grants, and amended the application documents to reflect changes and remove mentions of the national grants programme and team.

The new guidance and documents are available to download from the Volunteer Website at volunteers.mssociety.org.uk/MS-Society-grants.

They include:

- **Grant-giving process overview:** a summary of the key stages in the grant-giving process
- **Grant giving – good practice guide for groups 2021:** a more detailed overview of awarding Health & Wellbeing Grants and Carers Grants
- **Group grants record template:** a simple form to track your group's grant decisions and budget
- **Grants - financial assessment tool:** to help you prioritise applicants in most financial need
- **Quick reference list of grant categories and maximum grant amounts:** updated to show both the 2020 changes and the previous amounts
- **Additional funding information form:** to help you gather information from a grant applicant to try to find other sources of funding (if your group offers this support)
- **Updated Health & Wellbeing Grant application form and guidance notes**
- **Updated Carers Grant application form**

During 2021, we'll be working closely with groups to develop local grant-giving best practice, training, guidance and support. Look out for details of Zoom sessions in May, where we'll start having conversations about what the priorities are for groups. We'll also be looking for volunteers to get involved in a working group to develop grants processes and support materials.

Support for groups assessing grant applications
In the past, the national Grants Team assessed applications for groups that needed this help. As we no longer have a central Grants Team, we now don't have the capacity for staff to consider applications on behalf of groups.

We'll be working with groups to explore possible solutions to this situation. In the meantime, we'd like to suggest that some of our groups could work together on grant giving. So, if you have the funds to offer a grant, but can't assess an application, you could ask another local group that is experienced in considering grants to assess the application for you.

The Volunteer Support Team (0300 500 8084 #3 or volunteersupport@mssociety.org.uk) can give you details of groups that are local to you, so that you can get in touch to find out if they're able to help. At the moment, we can't tell you which groups will be in a position to help, but we'll be building up this information so that we can help link groups up going forwards.

If you're a group with experience of considering grants, and feel you can offer this support to other groups, please let the Volunteer Support Team know, so that we can start building this information.

Outstanding group achievements

2020 was challenging to say the least. We had to get to grips with a new way of life and learn new skills in order to stay connected with friends, family and each other online.

The dedication of our volunteers has not gone unnoticed. It's been inspiring to see how those of you who could, have kept in touch with group members and continued services and activities where possible to provide support for people with MS. To have done this whilst overcoming personal challenges brought by the pandemic has been an incredible achievement.

Adapting at speed

Before the pandemic, some of you had limited experience of video conferencing platforms, such as Zoom. But so many of you have faced the challenge head on, becoming digital pros in your own right, and sharing your knowledge to help others get online.

Ian Gourlay, one of our Finance Volunteers in Scotland, is part of our Aberdeen Group. He told us they had never used Zoom until their Community Development Officer suggested it. They now hold eight sessions a week, totalling 318 so far over the past year with 3,533 in attendance!

Staying active online

Other groups across the UK have also successfully moved fitness classes (such as yoga, Pilates, tai chi, dance, seated exercise and more) online with positive results.

Social events, including karaoke, quizzes, bingo, coffee mornings, pub nights and crafting, have also been successfully digitalised.

Some more unusual activities have also been on offer. Hull, Beverley & Holderness worked on a ten-week creative project via Zoom, led by the Hull Truck Theatre Company, and Dundee have joined with the Tayside Health Care Trust to offer creative writing and photography classes.

Many people with MS who experience fatigue have reported that, without the travel to classes and social get-togethers, and with the option of attending only part of a session, these events have become much more accessible. So, whilst we're all looking forward to meeting again face to face, we'll continue to encourage and support groups to deliver online activity where there's a need.

Outstanding group achievements

National and international reach

Taking activities and services online has also led to an increase in attendance. This is largely because their physical location doesn't matter, so wherever you are in the world you can join a session online. And this is exactly what happened for the Aberdeen Group when a participant's family member in the United Arab Emirates joined a session.

In Ayrshire, the Kyle Group had international interest too. Someone from the Latvian MS Society joined one of their socials.

And the Caerphilly & District Group have been holding a quiz attended by people from all across Wales.

Increasing reach like this when people with MS have needed support more than ever is such a positive outcome.

Going above and beyond

There are so many ways our groups have gone above and beyond to ensure they can keep their members connected and reduce isolation.

A number of groups have successfully applied for grant funding (either locally or through the National Lottery), which has been used to fund online activities and, in some cases, to provide tablets or smartphones for members to get online.

An example of this is our North Staffordshire Group which was awarded £2.5k from a Local Authority funding pot, set up to support local charities during the COVID-19 crisis. They applied for funds to purchase large screen smart phones to be distributed to those with MS in the area who didn't have access to such devices. This has given them opportunities to join in with socials on Zoom and WhatsApp, as well as keeping connected with friends and family. If your group would like to apply for the National Lottery Community Fund (Awards for All), check out our eLearning module on the Volunteer Website which explains what you need to do at volunteers.mssociety.org.uk/awards-for-all.

The Newry Group in Northern Ireland also successfully applied for some local funding before Christmas, which was aimed at brightening up people's lives during lockdown. The funding received allowed them to deliver a poinsettia plant and a box of chocolates to local people affected by MS.

The power of collaboration

We've heard how our group volunteers have been sharing more with each other and learning from each other about how to manage the tasks required to operate a group. And this has built a wonderful community spirit.

Tony Cardis, Group Coordinator of the York Group told us how they're now working with the Harrogate, Leeds and Tees & Esk groups. The groups have learnt from each other by using the skills and talents from each group. For example, the York Group does the online banking, SLAs are Leeds' strength, and Tees & Esk are the fundraising experts.

Tony and Jag, a Communications Volunteer from the Leeds Group, told us about some of the other benefits from partnership working. Cost savings have been made through sharing Zoom accounts and splitting the costs of fitness instructors. And there's been an impressive increase in the number of people attending their sessions.

It's also helped to build connections within our community. They told us that previously both the Leeds and York group would offer one face-to-face class a week and there might have been two or three people joining.

After moving the classes online, numbers rose to around 20 per class. With geography no longer a barrier, people now join from Rochdale, Teeside, Harrogate, Reading and Wales, ultimately giving those with MS the opportunity to meet others from outside of their areas.

In short, this partnership has been a huge success! They've gone from supporting fewer than ten people each week, to around 100 each week – amazing!

Another example of successful collaboration between our groups has been the partnership between two of our Scottish Isles, Orkney and Shetland, who have come together to provide Mindfulness sessions. By joining forces, their members have got to know each other better, which has led to social Zoom sessions afterwards too!

And our groups have been supporting each other in other ways. Another great example is how our Aberdeen Group have been sharing their newsletter with the members of a group unable to produce one.

We understand the importance of building and strengthening connections with other groups. So, we're planning to support you by providing more collaborative opportunities, such as Coffee & Chat sessions, and networking events, and through your Regional or Community Development Officers.

Outstanding group achievements

Wider recognition

Your dedication hasn't gone unnoticed by our organisation, or others!

Last year, the Isle of Wight Group received royal recognition for the outstanding work they've been doing in the community and were awarded the Queen's Award for Voluntary Service.

The Queen's Award is the highest award a voluntary group can receive in the UK and is equivalent to an MBE. The award represents deserved recognition for the volunteers, the dedicated Shop Manager, and the Coordinating Team for outstanding efforts in supporting those living with MS on the Isle of Wight. The group offers support to over 40 people who are living with MS or have a connection to the condition.

Group Coordinator Paul Brading said: "I am absolutely delighted that all the great work everyone in the group does has been recognised with this amazing award".

Our MS community has also been appreciative of the ongoing support given by local groups.

During Volunteers' Week last year, Mark from the Gwynedd/Ynys Mon Group told us how important staying connected during lockdown has been to him. Mark said: *"The MS Society choir meet up on Zoom every Friday too, led by an award-winning professional Natural Voices choir leader. Being able to meet up online and have a sing together is brilliant. The MS Society have really come through for us during coronavirus, and in such a short time. It's been tremendous"*.

Soulla said about her local Sutton Group: *"These angels have been there for all of us with advice, comfort, and loads of activities. Whenever you need them, they are there"*.

Sam, a member from the Larne Group said: *"That's the best part about the MS Society groups: the people you meet. We're a family. We always look after each other. We share knowledge. We have a laugh together. We cry together. Just the way a family does"*.

And Robert, a member of the Lanarkshire Group, told us just how important the activities that local groups provide are. Robert said: *"If it wasn't for the local MS Society group taster session, I don't know what I would have done. It opened up my mind to try new things and try sports. My personality has changed as well, I've become livelier. Activity like this opens up a network of people and can help with living with MS so much, improving mood and symptoms"*.

Outstanding group achievements

It's not all about digital

There have been so many stories about the time and dedication put in by our group volunteers to make regular calls to those without online access. Our Mid Ulster Group continued to support people on a monthly basis via the phone, which has been particularly important to those in rural communities.

Some group services have been able to continue without needing to be adapted, including telephone counselling and remote access partnerships with Citizens Advice. Whilst others have been keeping regular communication through their newsletters, with printed copied being delivered to those without online access.

The support provided by our groups has ensured no one had to face the pandemic and MS alone.

Thank you

These are just a few of the ways our local groups have supported the community where possible. Last year was difficult for so many, but we couldn't have continued to be there for people with MS without you. Thank you for all you've done and continue to do!

Research during the pandemic

Research was high up 2020's news agenda, as we followed the twists and turns of global vaccine developments and trials, hoping that science would help us out of the pandemic.

But what happened to the research we fund into treatments to help people live better with MS, and our ultimate mission to stop MS altogether?

As the UK entered the first lockdowns, more than 70% of the researchers we fund reported significant disruption to their work. Many of our clinical studies require face-to-face appointments which couldn't happen, and a lot of research staff were redeployed to help the NHS. We did everything we could to keep existing projects going. Clinical trials staff adapted so they could carry out follow-up visits remotely. Lab workers analysed results and wrote up findings from home. And MS researchers across the world kept in touch and shared ideas virtually. But we had to delay or pause a lot of our research.

COVID-19 impact

In response to the pandemic, we supported the UK MS Register to run regular surveys to help understand how COVID-19 was impacting people with MS. People reported any changes they'd made to their behaviour and treatments, and any relevant symptoms.

Results released later in the year showed that during the early phase of the pandemic, when strict lockdown measures were taken, people with MS had a similar chance of getting COVID-19 to the general population. Importantly, the data reinforced that self-isolating greatly decreased the risk of contracting the virus.

As 2020 progressed, researchers were able to access their labs (with strict social distancing), and recruitment to clinical trials began to gather momentum again.

Research during the pandemic

New research results

In August, results of research we part funded suggested the diabetes drug pioglitazone could be another piece in the puzzle of stopping MS. In MS, nerves carry messages less efficiently and need more energy to compensate for this. Researchers discovered that nerves have the natural ability to boost their energy supplies after being damaged. Excitingly, pioglitazone can further increase energy supplied to the damaged nerves in mice, and protects them from additional damage.

In September, we shared results from our clinical trial which showed that bexarotene (a drug developed to treat cancer) can regenerate lost myelin in people with relapsing MS. Myelin is the protective coating that surrounds nerve fibres, and is damaged in MS. Understanding more about how it can be repaired is a critical breakthrough.

Unfortunately, participants in the trial experienced some serious side effects, so bexarotene won't be taken into a further study. But the lessons learned will be taken forward to new trials. We were proud to announce our new trial of the diabetes drug, metformin, which in 2019 was shown to boost myelin repair in rats. In this trial, people with relapsing MS will test metformin in combination with clemastine (an antihistamine). It's hoped that these treatments used together will be safe and effective, and could help prevent disability progression.

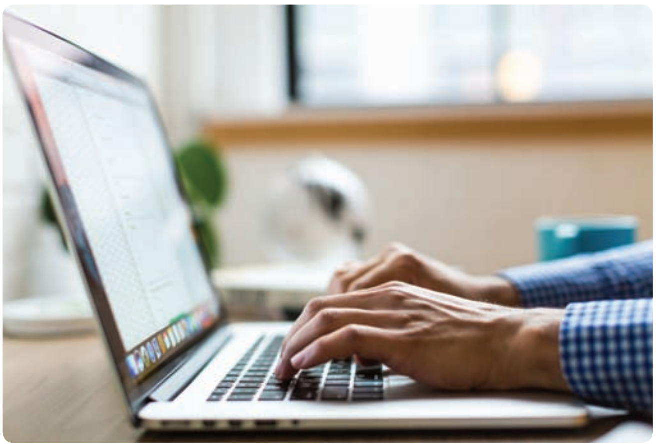
Clinical trial

One trial able to go ahead was phase 3 of our MS-STAT2 trial, testing whether a cholesterol-lowering drug, simvastatin, could help people with secondary progressive MS. Researchers will test whether simvastatin can slow disability progression over a three-year period. If the trial is successful, simvastatin could be one of the first treatments licensed for secondary progressive MS.

We're delighted that, through the many challenges of 2020, the dedicated researchers we fund found ways to progress their ground-breaking work towards stopping MS. We're also very grateful to our supporters and groups who continued to donate towards the research we fund. Although research is facing new challenges, we're still on the cusp of a major breakthrough. COVID-19 might have slowed down our progress, but we're still going to stop MS.

Support during the pandemic

Supporting the MS community is always one of the most important things we do, whether that's by providing practical information or giving emotional support. When the pandemic struck last year, these services became even more vital.



The start of lockdown showed a steep spike in calls to our Helpline, with people concerned and anxious about everything from getting their shopping to continuing their DMTs.

So, from the start, and throughout the pandemic, we kept our website regularly updated with care and support information around COVID-19 from across the four nations, responding to changes in governmental advice. And we published guidance from our medical advisors on particular issues around COVID-19 and MS. For those without online access, we created an information sheet which could be printed out for them.

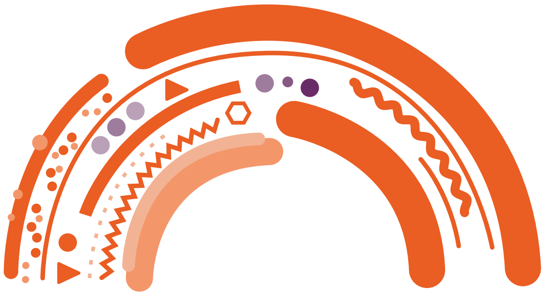
We also increased our programme of information webinars, with expert speakers helping people to understand how the current crisis would affect them and their MS, and taking questions. And we were glad to recruit the first of our two MS Nurses to the Helpline at this time – a service which has proved very popular.

Combatting isolation

With so many in our community being advised to shield, we knew that practical advice was not enough, and that isolation was a threat to mental health.

So, our wonderful Helpline Team worked quickly to develop a new 'Keep in Touch' service, where particularly vulnerable members of our community could register for a weekly call from a friendly volunteer – just for a chat and to see how they were doing. 35 of our colleagues volunteered for 'Keep in Touch', and we supported 40 people, with 467 calls completed between April and September.

We also launched our 'Time to Chat' service, for people from the MS community to come together online in small groups alongside a member of staff. These sessions offered a space to talk about the issues that were affecting them and share top tips on living well with MS.



Never alone.

Together, we will be there for everyone affected by MS

Support during the pandemic

Some support highlights from around the UK

In May, our team in **Scotland** were delighted to achieve funding to launch a 'Wellbeing Hub' to keep people living with MS connected during the pandemic. The Hub offered services to support both physical and mental health, including one-to-one calls, counselling, financial wellbeing and physio support, information webinars, virtual socials, and online exercise.

The Hub was instantly a hit with our community. During the initial funding period from June to September, 359 people with MS accessed the service and 75% of individuals said the way they felt (their mood) improved after taking part in one of the Hub's services. Our supporter, Carla, described the service as 'phenomenal'. We're delighted to continue delivering this service into this summer.

In **Wales**, our very successful 'My MS, My Rights, My Choices' project had been due to end in April, but we managed to obtain additional funding to extend to September. During this time, our staff provided one-to-one support to 147 people. And they made weekly calls to 15 isolated people with MS, who were mainly older and had no family or friends to contact during lockdown. They ran 'Time to Chat' sessions, information webinars and an eight-week Mindfulness course. The team also worked to refer isolated people with MS to community voluntary councils who could organise volunteers to deliver medication and shopping.

Over in **Northern Ireland**, we secured a total of £155k from The National Lottery Community Fund from November 2019 for the Mind My MS Project. Once the pandemic struck, we quickly moved planned face-to-face services online to ensure we could continue being there for the community, and we supported over 100 people with MS online during 2020.

Mike, a member of the community who accessed some of the project's services told us how they helped him stay connected. He said: *"Like a lot of groups, it's been a difficult time over the pandemic to have MS. The younger persons' MS Cafes run by the MS Society have been a good opportunity to stay connected, discuss issues faced during COVID, and just to have a general chat. I've attended quite a few cafes and they've been really enjoyable and a great encouragement."*

Helping you to help others

Of course, a very important element in our ability to support the MS community is you – our volunteers and groups. In true style, those of you who were able to found new ways to connect with your members and service users, to ensure that nobody felt alone. Much of the one-to-one support given by Support Volunteers and Group Coordinators is challenging at the best of times – let alone during the anxiety caused by a global pandemic. So, our Support & Wellbeing Team (Deborah and Barbara) were glad to support those volunteers through a series of online forums for connection, discussion, problem-solving, or just a cathartic chat. And their door remains open, so you can always contact them via the Volunteer Support Team (**volunteersupport@mssociety.org.uk** or 0300 500 8084 #3).

Fundraising during the pandemic

With the UK in lockdown and under restrictions, fundraising in 2020 was extremely challenging. All the big events such as marathons were cancelled, and local group activities like street collections had to be stopped. But MS doesn't stop for anything, so neither could our fundraising. We needed to bring in money to support our community through the crisis, and to continue our ambitious Stop MS Appeal to raise £100m by 2025 for MS research.

STOP
MS

To inspire our supporters to raise money whilst staying at home, our wonderful Fundraising Team came up with a whole host of online fundraising ideas (mssociety.org.uk/get-involved/fundraise/ideas-for-fundraisers/fundraising-at-home), from doing a spring clear out and donating the proceeds from eBay, to sponsored head shaving or beard growing.

The team also found innovative ways for more energetic fundraising activities to continue...

Keeping moving

We all knew the importance of fresh air and exercise to keep us physically and mentally healthy during lockdown. And many of you combined this with raising money to help us stop MS!

The hundreds of people who took part in 'My MS Walk' and 'MS Walk Live' raised an amazing £160,000 for vital research by walking up and down stairs, strolling around the garden or rolling to the park.

Then there was our brand new '100k Your Way' challenge. We challenged you to run, walk or cycle 100k yourself, or split the distance between your friends and family. It could be completed at any speed, even if it took days or weeks. Again, our supporters rose to the challenge to raise an impressive £202,000. In November, we got our trainers out one last time to launch our virtual running challenge – the 'Big MS Run Off'. This was a friendly competition, with participants across the UK divided into teams, headed by two of our MS Superstars. Individual runners did as many miles as they could during the month, adding to the combined distance for their team and raising another fantastic £40,000.

Fundraising during the pandemic

Famous faces

The early months of lockdown, when Zoom was still quite a novelty, saw a sudden craze for virtual pub quizzes – and the 'MS Society Pub Quiz Live!, hosted by our Ambassador, Radio 1's Scott Mills, was an instant hit! And celebrities including Andy Serkis, Maisie Williams, Alan Carr, Mollie King and Sir Cliff Richard filmed themselves asking questions.

MS Society
Pub Quiz
Live!

Throughout the year, celebrities continued to support our work in new and exciting ways. In June, we launched our 'Never Alone Silent Auction'. Bidders could win 'money can't buy' masterclasses with well-known names in business, entertainment and sport, including singer Emeli Sandé and Dave Myers from the Hairy Bikers.

As we moved towards the festive season, there were more opportunities for our supporters to engage with celebrities. Michelin-starred chef and restauranteur, Tom Kerridge, hosted a virtual cook along. And wine expert and critic, Jancis Robinson, held an online tasting of exclusive wines.

Scott Mills returned with a Strictly Come Dancing quiz and then a Christmas quiz. In total, 23,000 people raised a fantastic £62,000 over his eight quizzes in 2020, live-streamed on our social media channels. And the year was rounded off by Dave Myers hosting our 'Carols by Candlelight' concert from his front room, with readings from Emilia Fox, Robert Powell and Laurence Llewelyn-Bowen.

Around the UK

Northern Ireland

Throughout the pandemic individuals, families and organisations continued to take on incredible challenges to raise money to support the MS community in Northern Ireland. From online quizzes and poetry writing to virtual cycling or taking part in our Big Leap skydive, our supporters and volunteers found new and exciting ways to fundraise. We look forward to seeing what they get up to in 2021.

Scotland

In August, we held our first socially-distanced event with 24 amazing #MSSuperstars. We adapted our Ben Nevis Night Hike to be COVID safe and supported our fundraisers to hike the highest mountain in the UK through the night. Together they have raised over £26,000. We're looking forward to our next Ben Nevis Night Hike in August this year.

Wales

Our MS superstars haven't let the pandemic stop their fundraising efforts; from running 7 half marathons in 7 days, to raising hundreds of pounds with Christmas baking; from music teachers covering 'Do They Know It's Christmas', to Aberystwyth Town Ladies FC's doing a virtual North Pole Challenge; and our incredible Atlantic Dragon Gareth rowing 3,000 miles across the Atlantic Ocean, raising over £50k. Diolch yn fawr pawb! Thank you all!

Fundraising during the pandemic

What next?

We're so grateful to everyone who has continued to support us during 2020, from individuals completing active challenges to local groups organising online quizzes and cake bakes. Your determination to keep going through the difficulties of the pandemic has been inspiring – and we hope you've had some fun doing it as well.

As we cross our fingers for a slow restoration of 'normality' in 2021, we can look forward to the return of more traditional fundraising activity. And we're committed to supporting our groups to resume their fundraising, and helping them find new and better ways to increase their income. If you'd like to hear more about this, come along to our Volunteer Voice event on Wednesday 26 May. Details are on the Volunteer Website 'Events' page, or you can sign up here: eventbrite.co.uk/e/volunteer-voice-tickets-149688360917.

Campaigning during the pandemic

Our commitment to campaign and influence policy to make positive change for people affected by MS was never stronger than last year.

Through the rapid changes and uncertainty of the pandemic, we worked to champion the rights of those affected by MS and make sure we weren't forgotten.

Here are some highlights of our work in 2020:

Accessing essentials

During the first lockdown, many in our community faced challenges getting food and essentials – particularly home deliveries. So, we brought together a group of 24 charities to successfully campaign for the UK Government and supermarkets to ensure sure those in the MS community who were at greater risk had priority access to supermarkets and deliveries.

Too much to lose

As a result of COVID-19, routine appointments, therapies and treatments were cancelled or delayed. Seven in ten people with MS told us they hadn't been able to speak to a rehabilitation professional when they needed to during the pandemic. We know how important these services are for people and needed to make sure decision makers didn't forget it.

We launched our Too Much to Lose campaign, calling on health leaders to improve rehabilitation services for local people with MS. Thousands of people emailed their local health leaders and hundreds wrote letters to local papers to raise awareness. We also took the campaign to the UK Parliament to raise the issue directly with MPs and the Health Minister.

We're now in touch with a number of health organisations to help improve rehabilitation services UK wide. And we're keeping the issue on the UK Government's agenda.

Fairer financial support

As a leading member of the Disability Benefits Consortium (DBC), we've continued to campaign to increase benefits such as Employment and Support Allowance (ESA) to match the £20 uplift given to Universal Credit claimants. It's unfair that some people are receiving more financial support than others when we know many have additional costs as a result of COVID-19. Nobody should have to choose between heating and eating.

Together we've supported a 115,000 strong petition, raised the issue with MPs and spoken out in the media.

Campaigning during the pandemic

More treatments available in more places

Siponimod is the first ever oral treatment for people living with active secondary progressive MS. This important treatment offers hope to lots of people with MS, but it was originally rejected for use on the NHS in England and Wales. The MS community played a vital role in speaking out and reversing that decision.

Thanks to those who highlighted how important this treatment is, siponimod is now approved for use on the NHS in England, Scotland and Wales. We expect a decision to follow in Northern Ireland in the coming months.

In **Scotland**, we've seen even more treatments made available. Ocrelizumab (the first treatment for active primary progressive MS) and ozanimod (for relapsing MS) took the number of DMTs available on the NHS in Scotland to 15. We've also had fampridine approved for use, which is a symptom management treatment (SMT) for people with a walking disability and can help increase walking speed. This is thanks to people with MS who shared their experiences to make a case for these essential treatments.

In **Wales**, we continued to campaign to ensure that treatments approved for use are made available without delay. We're sharing the experiences of people living with MS with the Welsh Government and decision makers to ensure that there's more capacity within the NHS in Wales to make treatments available to everyone who's eligible for them.

In **Northern Ireland**, we've continued to represent people impacted by the recall of neurology patients under the care of the Belfast Trust.

Waiting times and access to services in Northern Ireland were an issue even before the pandemic, so this is an issue we've also continued to campaign on. As members of the steering group of the Neurology Review, we're awaiting the restart of that process so we can continue to play an active role in shaping and improving the services people living with MS receive.

We've also been actively campaigning to improve the consistently negative experiences of people applying for Personal Independence Payments (PIP) in Northern Ireland.

We gave evidence to the second independent review of PIP. A report has now been published and is currently awaiting government response.

We'll continue to campaign on the issues that matter to people affected by MS. But we can only do it together. Join our Campaigns Community (signup.mssociety.org.uk/page/21905/data/1) to stay up to date on all our campaigning activity.

Things to look forward to in 2021

Whilst things were tough last year, it didn't stop us from looking ahead and planning for brighter days. Here are just a few key things to look out for in 2021.

Campaigns

Speak out to tackle local issues facing people with MS

Too many people with MS in the UK have to fight for the treatments, services, care and support they need. Often getting the right services and support comes down to local decisions.

So, this year, we've launched Local Action for MS, an exciting new range of activities and resources to support you to campaign for change in your local area.

Whatever action you take, it all makes a difference. Campaigning can be small actions like sending an email or a tweet, or a large-scale campaign event like a protest or demonstration.

You might be starting out alone, with your local MS Society group or alongside other campaigners. Whatever you're planning, we can support you to help make it happen.

In partnership with a group of people with MS, we've developed a toolkit to give you ideas and inspiration on how to raise your concerns. Find out more about the new resources and success stories from other campaigners on the Local Action for MS web page by visiting mssociety.org.uk/get-involved/campaign-with-us/local-campaigning, which includes online tools to help you succeed.

Become a volunteer Campaigner

You can also sign up as a volunteer Campaigner by visiting candidate.mssociety.org.uk/ms/volunteering/campaigner and we'll support you to lead your own campaign.

By signing up you can access our comprehensive training to expand your skills, and be able to connect with others working on similar issues. The training sessions include campaign planning and tactics, as well as ideas on how to get your message across in a range of ways. We also have sessions on influencing MPs and local councillors, with a local MP and councillor providing advice and answers to your questions.

Making a difference

You know your local area best, the issues you face and the impact this has on your local community. If you're not getting the services and support you need, speaking out can change things.

If you have any questions about our volunteering opportunities, or would like to speak to a team member, please get in touch via signup.mssociety.org.uk/page/66912/data/1 or email campaigns@mssociety.org.uk.

Things to look forward to in 2021

Change things by telling your story

You can also help us to change things by sharing your story. By explaining how MS affects you, or how other things like access to benefits, care, support or treatments impact you, you can help us challenge and change government decisions.

We want to hear from as many people as possible to understand your experiences. At the moment we particularly want to hear experiences of having carers come to your home, or getting support for your day-to-day activities like going to medical appointments or getting essentials, ahead of UK Government proposals to improve services.

Please share your story by emailing campaigns@mssociety.org.uk. If you'd rather talk to one of the team, just let us know in your email, giving your phone number and the best time to call.

Fundraising

Coming together in 2021

We know how difficult the past year has been, but we're so proud of how you have all come together for the MS community. Now there's hope on the horizon, we can't wait to get out and see you all again at fundraising events across the country! Here are just a few of the fun things you and your community can get involved in this year.

Walk, roll or stroll to stop MS

In 2021, My MS Walk is back and bigger than ever, and we need you! Keep active, be part of a special virtual community and raise vital funds to help stop MS.

Simply sign up and get walking, rolling or strolling throughout June. You can log your miles and follow everyone's progress with leader boards and social media feeds on the My MS Walk Hub. We're also planning an exciting virtual event at the end of June to celebrate everyone's achievements! Find out more and sign up on our website at mymswalk.mssociety.org.uk/

We're also hoping to see you all in person at MS Walks in London, Bristol, Cardiff, Belfast and Edinburgh later this year. Check our website in May for more details.

Be part of the world's largest ever marathon event on Sunday 3 October

The 2021 London Marathon is set to be the biggest it has ever been, with a staggering 100,000 participants – 50,000 of those taking part in the Virtual Marathon. Taking part in the Virtual London Marathon is a chance to earn the coveted London Marathon medal and finisher's t-shirt in a more flexible way, by completing 26.2 miles locally with a 24-hour time limit. Your marathon, your way!

Secure your MS Society place for £15, with a £175 minimum fundraising target. You'll receive lots of support from the Events Team on your marathon journey, including an invitation to our MS Society Team training day. Plus, you'll be raising those all-important funds for the MS community. Visit mssociety.org.uk/get-involved/fundraise/running/virtual-london-marathon-2021 for more information.

Take the Big Leap this World MS Day

Are you brave enough to take the leap of a lifetime at our exclusive Big Leap day on Sunday 30 May 2021?

Take part in our sky diving extravaganza to experience the thrill of jumping from up to 10,000 feet and free falling at over 120 mph.

Things to look forward to in 2021

Whatever your reason – celebrating a significant birthday, ticking it off your bucket list or getting an adrenaline rush, join our team and help us raise vital funds to stop MS.

There's still time to sign up to the Big Leap or pick a jump date of your choice. Find out more at mssociety.org.uk/bigleap.

These events are just a taster of what's to come. Visit mssociety.org.uk/get-involved/fundraise or email fundraising@mssociety.org.uk to find out more about all of our events. After such a difficult year, we can't wait to reconnect with you and hope to see you soon!

Research

Octopus makes its debut!

We're so excited to have recently announced our commitment to raising £12.9 million to fund a new clinical trials platform called Octopus.

It's the first time a clinical trials platform has been used in MS anywhere in the world! And Octopus will revolutionise the way we test treatments for primary and secondary progressive MS, delivering answers much more quickly than traditional trials.

Currently there's still nothing widely available for people with progressive MS that could slow or stop progression. We're excited that Octopus could ultimately change this by potentially leading to treatments for progression becoming available sooner.

How does Octopus work?
Like a real octopus, it's got multiple arms (albeit not eight) which will allow researchers to test several potential treatments against a single placebo (an inactive pill). This avoids running multiple separate trials, with the many associated costs.

Partway through the trial, we'll use magnetic resonance imaging (MRI) to see which drugs look promising. We'll then take these drugs to the next stage of the trial where we'll invite more participants to join, combining what would normally be two consecutive trials into one. Drugs not showing potential will be dropped, so we don't waste resources.

Using this design should mean we can test potential treatments up to three times faster.

Can people sign up?
No, the trial is not open for recruitment yet. We're hoping to announce the first drugs to be tested in early summer. People with progressive MS should be able to register their interest in the trial from the autumn. For more information about the plans for Octopus, as well as other trials looking for people with progressive MS to take part, please visit mssociety.org.uk/research/latest-research/research-blog/full-steam-ahead-our-mega-trial-progressive-ms.

Although COVID-19 slowed us down, we still plan to be in the final stages of testing treatments for everyone with MS by 2025.

We'll keep you updated on progress throughout the year.

New trial for people with advanced progressive MS

We're supporting a ground-breaking clinical trial called ChariotMS, which specifically focuses on people who are unable to walk.

Things to look forward to in 2021

There are currently no disease modifying therapies (DMTs) available for people with MS who aren't able to use their lower limbs at all, or can only walk short distances with help from aids like crutches.

In MS clinical trials, walking ability has traditionally been the key measurement of whether a drug is effective. This means many people who use wheelchairs have been unable to take part.

ChariotMS is changing that. The new trial will test whether a drug called cladribine, which is already used to treat highly active relapsing MS, can slow down the worsening of hand and arm function for people with more advanced progressive MS. If successful, ChariotMS could eventually lead to cladribine becoming the first available DMT for advanced progressive MS. This is a major milestone in MS research and we've committed to raise £370,000 to support the study.

A ground-breaking trial
This is the first trial of a potential DMT that focuses on people with advanced MS, regardless of whether their MS is primary or secondary progressive. And it's the first with no upper age limit.

Instead of using walking ability to determine whether the drug is effective, the trial will use a task called the Nine Hole Peg Test. This test measures how hand and arm function changes over time.

Why are we hopeful about cladribine?
Like all DMTs, cladribine is what we call an immunomodulatory drug – it stops the immune system mistakenly damaging the protective coating around our nerves (myelin). But, unlike some other DMTs, it can actually get inside the brain and spinal cord. This is why cladribine can be so effective for relapsing MS.

Traditionally, researchers thought this type of treatment wouldn't work very well in more advanced MS, because for these people damage is less likely to be caused by immune activity. But recent evidence suggests tackling the immune system with a drug like cladribine may actually still be effective.

Who can take part in ChariotMS?
The team will recruit 200 participants who score between 6.5 and 8.5 on the Expanded Disability Status Scale (EDSS). This means some people who have never been eligible for a trial before will be able to take part.

The trial team hope to start recruiting participants within the next few months. They're encouraging people who think they might be eligible to get in touch with their neurologist or MS nurse about a possible referral, or to email the trial team at chariot@qmul.ac.uk.

A powerful partnership
ChariotMS has been made possible by government, charity and commercial funders

coming together. It will be funded by the Efficacy and Mechanism Evaluation programme, a partnership between the Medical Research Council and National Institute for Health Research. It will also be receiving funding from the company who produce cladribine – Merck Serono – and from Barts' Charity, the National MS Society in the US and us.

Find out more about ChariotMS and how to take part by visiting mssociety.org.uk/research/latest-research/latest-research-news-and-blogs/new-trial-people-advanced-progressive-ms-starting-soon.

Digital and Services

Digital Health Assistant launching soon!

This summer, we're launching a new service we've developed that will provide tailored and targeted information and support to people with MS. It's called the Digital Health Assistant and will send email information about symptoms, treatments and wellbeing that's tailored to their needs.

We hope the Digital Health Assistant will make a real difference to people living with MS. We used insight from people with neurological conditions including MS to design the Digital Health Assistant and we've asked people with MS to help us test it. We'll keep you updated with launch plans nearer the time.

What's happening across our nations?

Pontio launches in Wales

We're delighted to have received almost £500,000 from The Big Lottery to fund a new three-year project in Wales. The project is called 'Pontio' and has been designed by a group of people living with MS in Wales.

Pontio means 'to bridge' in Welsh, and the project will be the bridge that helps to overcome the challenges faced by people with MS.

MS Society Cymru

PONTIO PROJECT

The Pontio Project provides emotional, befriending and one to one support to people living with and affected by Multiple Sclerosis (MS) in Wales.

We offer information and support on employment rights & welfare benefits (incl. PIP/ESA claims); ways to manage your MS; accessing treatments, health & social care services.

Information

Befriending

Support

Contact

0808 800 8000

mymscymru@mssociety.org.uk

www.mssociety.org.uk/wales

ARIENNIR GAN Y LOTERI LOTTERY FUNDED

MS Society Cymru

PROSIECT PONTIO

Mae'r Prosiect Pontio yn darparu cefnogaeth emosiynol a chyfeilliol, a chymorth un i un i gefnogi pobl sydd yn byw efo a wedi effeithio gan Sglerosis Ymledol (MS) yng Nghymru.

Rydym yn cynnig gwybodaeth a chefnogaeth ar hawliau cyflogaeth a budd-daliadau lles (gan gynnwys wliadau PIP / ESA); ffyrdd o eich MS; mynediad at ethau, gwasanaethau iechyd cymdeithasol.

Gwybodaeth

Cyfeillio

Cymorth

Cyswllt

0808 800 8000

mymscymru@mssociety.org.uk

www.mssociety.org.uk/wales

It will continue with elements of our previous My MS, My Rights, My Choices project which finished in 2020, and will support our MS community to:

- make informed choices about health and treatment options
- provide emotional wellbeing and improve social connections
- improve financial, employment and housing/accommodation security

We'll be improving understanding of MS by delivering awareness training from volunteers with lived experience of MS to employers and advice organisations. Pontio has also recruited volunteers to provide befriending support to the MS community in Wales.

Things to look forward to in 2021

The MS Society Cymru Team continue to support our groups and the MS community to keep connected, informed and supported. A host of online activities have been organised including a weekly quiz, bingo, yoga, crafts, choir and ‘Time to Chat’ sessions.

Many in the MS community are digitally inactive so some of our groups have successfully obtained funding to purchase devices and internet connection so that those who were excluded can join in with the activities.

Campaigning for change in Wales

Ahead of the Welsh Parliament election on Thursday 6 May, we joined forces with the Wales Neurological Alliance to raise a number of issues at five regional election hustings.

Our MS Matters Manifesto highlights that far too many people living with MS in Wales face barriers when accessing vital treatments, support and care. We’re campaigning to improve capacity within the NHS to ensure that people living with MS get the best access to all available disease modifying therapies (DMTs) and symptom management therapies (SMTs).

People living with MS struggle without the support they need to do the basics like getting washed, dressed and eating. We need the next Welsh Government to improve care and support services for everyone.

With responsibility for health and social care being devolved to the Senedd, we’re doing all that we can to campaign for change and hold our politicians to account in Wales.

Fighting for people with MS in Northern Ireland

In Northern Ireland we expect the resumption of the review of neurology in 2021. As members of the review steering group, we’ll work hard to ensure this delivers improvements to the neurology services for everyone.

We know people with MS, and those facing a MS diagnosis, struggled with extremely long waiting times before the pandemic began, so this is something we’ll remain focused on.

We expect further developments and progress in the recall of over 3,000 neurology patients under the care of the Belfast Trust. We’ll continue to represent affected patients and their families throughout 2021.

As we emerge from lockdown and face-to-face services resume, we’ll also be refocusing on disability assessments under the Personal Independence Payments (PIP) system. A recent independent review of PIP is currently with the Northern Ireland Assembly for consideration and we expect the recommendations to be implemented in 2021.

Help us get louder for MS in Scotland!

More than 15,000 people are living with MS in Scotland; one of the highest rates in the world.

The recent Scottish Parliament election was an opportunity to ask representatives from all political parties what their plans are for dealing with the issues that affect our community.

After speaking to people living with MS, we put together an MS manifesto that lays out our demands for the next Scottish Government, including the creation of a rights-based social security system.

Things to look forward to in 2021

While we're pleased by some of the progress made since the last elections, many of the issues our community faced in 2016 remain and the pandemic has had a massive impact.

This election, we turned up the volume once more and asked everyone to get even louder for MS to ensure the MS community's voices continue to be heard in Parliament.

You can help us get louder for MS by sharing your stories with us using the hashtag #LouderForMS.

You can read our full manifesto by visiting mssociety.org.uk/what-we-do/news/ms-manifesto-2021-scottish-parliament-election.

Campaigning for change to disability benefits in Scotland

In Scotland, disability benefits are changing. Adult Disability Payment (ADP) will replace Personal Independence Payment (PIP). The Scottish Government held a consultation on the proposed changes which closed in March 2021.

In our engagement with the Scottish Government, we've consistently highlighted areas that you've said need to improve when ADP is rolled out. We're pleased that the draft regulations address many concerns people living with MS have about PIP.

However, in the proposed plans, the Scottish Government disappointingly hadn't changed the 20-metre rule and are using the same rules and eligibility criteria for ADP as for PIP. The 20-metre rule means if you can walk one step over 20 metres, you won't qualify for the higher rate of mobility support.

The Scottish Government says it wants to see dignity, fairness and respect at the heart of the new system. But people with MS have told us keeping the 20-metre rule fails to uphold these values.

We launched a petition calling for the 20-metre rule to be scrapped and over 33,000 people signed it from across the UK. We'll keep the MS community updated on the final outcome of the consultation.

Teamspirit directory

Our offices

MS Society
MS National Centre
372 Edgware Road
London NW2 6ND
Supporter Care: 0300 500 8084

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

Get in touch

Volunteer Support Team
volunteersupport@mssociety.org.uk
0300 500 8084 #3

National MS Helpline
helpline@mssociety.org.uk
0808 800 8000

Support groups

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

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

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
020 8542 1712

Find us online

mssociety.org.uk

volunteers.mssociety.org.uk

facebook.com/mssociety

twitter.com/mssocietyuk