

# Volunteering *in* Action

Highlights from 2022



# Introduction



## Welcome to Volunteering in Action: Highlights from 2022

Here, we share how our incredible volunteers have helped us to support our community in 2022. And what a year it was as we all

adapted to a 'new normal' after the pandemic, and responded to the rapidly changing external environment.

The uncertainty caused by the ongoing conflict across the world, and now the cost-of-living crisis, is having a particularly significant impact on those living with MS in our community.

Despite this, we've continued to see the dedication and support of our volunteers in action throughout all parts of our organisation.

Our volunteers are providing valuable insight and contribution to our research. They're helping us to design and deliver services. They're providing help and information on our MS Helpline. They're also leading and governing our work and joining

us to communicate and campaign for change. And they're raising vital funds and building MS communities through our 240 local groups all over the UK.

Last October, we came together to recognise and celebrate the contribution of volunteers at our first Impact Awards.

Our Impact Awards were designed around six key themes: Supporting and Empowering, Sharing Skills and Expertise, Connecting, Informing, Influencing, and Fundraising. We've also used these themes to guide our look back at 2022.

I was delighted to join the event on the night and inspired to hear what our winners and finalists have achieved. Also celebrating with us at the awards was Sir Paul Curran, who joined us in 2021 as our Chair of Trustees.

A huge congratulations and heartfelt thank you to everyone who has supported us over the year.

**Nick Moberly**, Chief Executive Officer



**Paul says:** "I joined the Board in July last year and have been both moved and inspired by the commitment and passion of our volunteers.

Volunteers are involved in every part of this great charity. I appreciate the time you give to support those living with MS, advocate alongside those with MS and work with researchers trying to stop the effects of MS.

Thank you for all that you've done and continue to do, no matter what your role. You make an invaluable contribution, and we couldn't achieve our goal – for people to live well with MS – without you.

I hope you enjoy reading about all that has been taking place across our volunteer community over the last year. None of it would have been possible without you and I look forward to all we can achieve together in 2023 – 70 years since the MS Society was founded!"

**Sir Paul Curran**, Chair of Trustees

# Volunteering plans



“I’ve always thought it takes someone a bit special to volunteer. Time is precious and we all lead busy lives. And yet so many still make it a priority to give of themselves to help others.

As we look back and celebrate the fantastic achievements of our volunteers in 2022, I also want to share our plans to make us an even better place to volunteer. We look forward to working with you to achieve our ambitions. Thank you for your ongoing commitment and support.”

**David Light**, Head of Volunteering and Community Networks

At the start of 2021, we outlined our five-year plan to strengthen our community support and the experience of volunteering with us. The diagram below shows the work we’re doing to transform how we value, inspire and connect with our volunteering community.

Our Volunteering Vision has five key outcomes that set the direction for our work:

## Stronger communities

As the UK’s largest MS charity, we play an important role in making sure everyone affected by MS can access the support that’s right for them. As well as providing services, we want to create resources, pathways and partnerships to bring our community together.



# Volunteering plans

We'll continue to find new ways of extending our reach and connecting with new volunteers using our online communities and peer support network.

As we want to increase the diversity of our volunteers to reflect the wider MS community, we'll also be focusing on taking forward our Equality, Diversity and Inclusion action plan.

## Impactful local services

It's important that our services and support activities continue to meet the needs of people with MS and make a positive difference to them.

We're working closely with our volunteer groups and health professionals, and listening to the needs of people with MS, to help us develop better services.

We're also keen to connect more people to a range of support that's flexible, responsive and right for them – from health professionals, community groups and other partners.

## Joined up offer of support

People have told us that trying to understand what services we offer can be very confusing.

That's why we want to make it easier for everyone to find what they need – by joining the dots between what we provide nationally and what we provide through our local groups.

Behind the scenes, we're also improving the day-to-day experience of volunteering by developing our policies, procedures and recruitment processes. But there's much still to do.

This year, a number of projects will focus on improving and simplifying our systems.

You may be familiar with our volunteer website and Portal, which give volunteers the information they need to carry out their roles. These systems are not particularly easy to

use – and it can be difficult to find the information you need – so we're retiring them at the end of 2023.

Ahead of this, we're embarking on a large-scale project to create a new Portal and will work closely with our volunteers to get it right. The new version will link to our database and eventually provide a 'one-stop shop' for everything our volunteers need.

This longer-term development of our volunteer website and Portal is part of our wider systems review, Project Sage. In the short term, we're planning an audit and review of the most frequently used content on the volunteer website to improve the experience of using it.

## An engaged and appreciated volunteer community

Volunteers are the lifeblood of our organisation, providing us with the energy and impetus we need to continue our work.

We listened to their feedback and were delighted to launch our new Volunteer Recognition Scheme at the start of 2022. It's an important opportunity for us to thank them, and acknowledge their years of service and the positive difference they make to those living with MS. We're keen to continue celebrating and raising the profile of volunteering by sharing more of the brilliant work they do across our community.

Several projects have reviewed our induction process for new volunteers and how we can provide a more consistent and welcoming experience.

We'll continue to run our Welcome Events to enable new volunteers to network with others while learning more about our charity. And we've recently launched a new Welcome Pack to provide a single point of reference on how we can support them.

# Volunteering plans

## A supported and sustainable network of volunteer groups

Volunteer groups play an important role in providing services and activities for our community. But we recognise that it can be difficult to keep up with our compliance requirements.

Our Volunteer Support Team welcomed two additional members last year and will continue providing local groups with day-to-day support and guidance.

Our Community Networks Advisory Panel, a group of volunteers from across the network, are currently reviewing our support structures. They'll provide recommendations on ways we can improve the support we give to our local groups.

We'll also be reviewing our Group Handbook so that all groups have up-to-date guidance and support to operate safely and effectively. And we'll continue offering opportunities for groups to collaborate and share ideas through our online forum and Coffee and Chat sessions.

We know that the nature of volunteering is changing – people have less time to commit to formal roles and are looking for flexible ways to get involved. That's why we're introducing new, lighter touch volunteering opportunities to encourage more people to join us.

We'll continue to develop our suite of training for volunteers so we can provide a variety of learning opportunities to support them in their roles.

## Volunteering in 2022

### Volunteer network



**389**  
new volunteers  
joined the  
MS Society



We have  
**2,907** volunteers  
supporting the MS community  
across the UK



The average  
age of  
new volunteers  
is **42**



**101** volunteers  
received one of our new  
**Impact Award**  
certificates

### Local groups



We currently have  
**237** active  
local groups  
across the UK



**170** local groups  
are delivering an  
**MS Support**  
service



**96%** of local groups  
have a  
**Finance Volunteer**  
currently in place



**83%** of local groups  
have a  
**Group Coordinator:**  
including 30 new ones

# Supporting and Empowering



The Volunteer Support Team (VST) worked hard over the last year to support our local groups as they restarted their activities after the pandemic. Our team was impressed with the variety of activities and support that they were providing to the MS community.

Examples included information and research talks, cook-alongs, virtual choirs, book clubs, chair-based Zumba, mindfulness and complementary therapies. The list is long and these activities have helped to reconnect people through shared interests and experiences.

Our team supported group volunteers by giving advice and guidance on how to run activities safely. They've also enjoyed seeing groups working together to share resources and expertise and respond creatively to meet local needs.

## Working together to develop services

Five groups in the Yorkshire area have strengthened the support they can offer, by joining together to build their communities and learn from one another. The collaboration was originally between the Leeds and District Group, York Group, Ryedale and District Group, Harrogate and District Group and Tees and Esk Group. The Hambleton and Richmondshire Group has since joined to widen the reach even further.

These groups work brilliantly together and have learnt from each other by pooling their skills and expertise. If one group is unsure about any new policies or processes, or needs some help one of the other groups will most likely have the knowledge to advise.

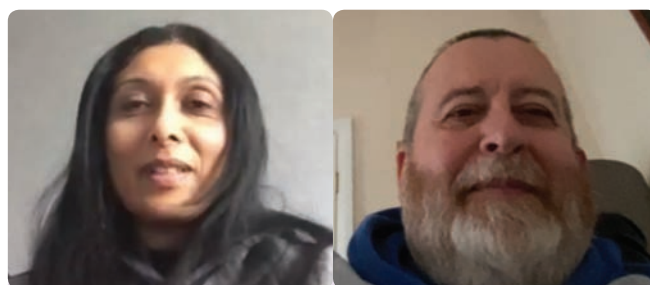
### How the collaboration works

This partnership works especially well when it comes to organising social activities and exercise sessions. All five groups play a part in hosting these sessions and will help each other to cover them.

Jagruti, Communications Volunteer from the Leeds and District Group, communicates once a week with group members. She uses text messages to inform them about upcoming activities for the week as well as on the day. She also posts updates on each group's Facebook page, tagging the relevant instructors and hosts. All sub-team leaders have contact details for the instructors, so if they have concerns they can notify them or Jagruti directly.

### Successful outcome

By working collaboratively, these groups have been able to offer people across Yorkshire a wider range of online activities. And running more frequent sessions means that more people can attend at a time that's convenient to them. This also provides the opportunity to build more connections with people outside of their local area.



Jagruti Suryavansi from Leeds and District Group and Tony Cardis from York, Ryedale and District Group

# Supporting and Empowering

**Jagruti said:** “To come together as one big family gives us the drive to help each other through facing the same condition (MS) as we can share our own personal experiences and provide comfort to one another.”

Between seven and 10 people attend each session – that’s at least 35 people a month in total. And group members who attended gave great feedback on these sessions and were impressed with the way their groups have pulled together.

**Tony said:** “The best support you’ll receive if you have MS is from those in the same situation. We’re here for each other.”

As well as information and resource sharing, Tony and Jagruti have told us about other benefits from partnership working. Cost savings have been made through sharing Zoom accounts and splitting the costs of fitness instructors.

## Working together to provide financial support

MS Society grants can make a huge difference for people affected by MS, helping them to pay for items that improve their health and wellbeing.

Unfortunately, not all local groups are able to offer grants. Some groups simply don’t have enough funds, while others don’t have enough volunteers to form a confidential grants panel, which is an essential part of the grants process.

So, with support from the VST, it’s been really positive to see groups coming together to help each other by offering a grants service to local MS communities. With more groups adapting to working online, they’ve been able to form new connections across the UK in a way that wasn’t possible previously.

The Perth and Kinross Group was one of several that came forward to help.



**Kathleen, a Coordinating Team member from the group, said:** “We’ve worked together to support the Nottingham Group and Scunthorpe and District Group with grant applications, particularly when they’ve received applications from their own group members which needed independent assessment. We’ve enjoyed being able to connect more broadly online with other groups who just want some general advice and to share experience. I’ve benefitted from chatting to them and hearing how things are for them now.”

A big thank you to all groups that have shared their time and expertise to support the grant application process. They ensured people affected by MS get the financial help they need.

## Relaunching how we connect with our group community

Over the last year, the VST has reviewed internal processes to improve efficiency and maximise the time available to support volunteers. They’ve trialled new ideas and ways of working, including reviewing frequent enquiries and turning these into Top Tips to share in the monthly volunteer e-newsletter.

# Supporting and Empowering

Our virtual Coffee & Chat sessions were a particular focus for improvement in 2022. After getting volunteer and staff feedback, we know that attendance levels, as well as content between the different sessions, varied greatly. These meetings were also really time intensive for the team to run on a regional basis. So, we decided to pool resources, consolidate the meetings, and offer new virtual sessions open to all volunteers across the UK. This means our volunteers are now able to access the same information, at the same time – improving the quality of information provided and overall experience.



A big thank you to everyone who attended the first of our new Coffee & Chat online meetings and completed the feedback survey. You provided lots of comments on what works well and what could work better, plus plenty of ideas for topics to cover in the future.

We relaunched our new national Coffee & Chat in September. Since then, we've seen attendance increase by 50%, with a broader group of volunteers from across the UK joining us. We even had to put on additional sessions as a result. We're continually gathering feedback, which has been hugely helpful to plan for future sessions. We want to make sure there's a good mix of opportunities to hear updates and information relevant to local

groups. And we want to offer our volunteers the chance to get together informally for a chat, or just to pop in online to ask a quick question.

**John, Group Coordinator from Lewisham, said:** "Coffee & Chat reminds us we are part of something bigger and there are others out there grappling with the same challenges locally. It's a great forum for sharing ideas and experience and very convenient online."



"We've really enjoyed working with you, meeting you and learning about what you're doing in your groups. We're here to help you turn your ideas and plans into reality. I can't wait to see what we can all achieve together in 2023!"

**Lauren Sampson, Volunteer Support Manager**

## Bringing the South and West Cornwall Group back to life



The South and West Cornwall Group had been closed for a few years when **Fiona Salamone** was recruited as the new Group Coordinator in May 2021.

Over the first few months, she recruited a team of volunteers using the MS nursing Zoom calls at the local hospital as well as social media.



# Supporting and Empowering

Together, the new volunteers relaunched the group in September 2021 and have since been providing invaluable support to people living with MS. The growing number of attendees at their meetings shows the need for connection and support in the area. And now, with around 50 people attending each month, they've had to find a bigger venue for their meetings.

The topics they cover (from fitness to benefits support), and the monthly outings they arrange, all focus on enabling people to live well with MS.

## Securing partnerships and funding

The group has teamed up with Age UK Cornwall to provide transport for people to get to appointments such as hospital and physiotherapy.

And they've partnered with Citizens Advice to get advice on benefits and employment across four sites in Cornwall. This has been funded for 12 months by a National Lottery grant worth £10,000. They've also received a grant worth £1,200 from Active Cornwall, which pays for their fortnightly exercise group.

**Fiona said:** "There's such an amazing team of volunteers in Cornwall that has been so pivotal in turning the group around and offering their expertise.

The biggest highlight in my role as Group Coordinator has been getting people back together. To build this group and see that people know they have support now no matter what is fantastic.

We've had a great year and hope to build on our growth in 2023."

## Providing support and guidance

Over the last year, our Support Volunteers have continued to offer invaluable support to people affected by MS. As one of our local group services, they're specially trained to:

- offer emotional support
- give information
- signpost people to relevant local and national services
- support with group grants

We attracted 33 new Support Volunteers in 2022, who are continuing to make a huge difference to our community. Feedback from our recent user survey has been 100% positive.

## Support from our staff

The staff Support Team continues to provide our volunteers with training, workshops, forums, bespoke sessions and ongoing one-to-one support if needed.



### Support and Wellbeing Facilitator

**Barbara Sujecka** is an experienced counsellor who's supporting our Support Volunteer programme and some other volunteer roles.

If you have any concerns

or anxieties related to your volunteering role, you can ask for a confidential chat. Barbara will provide a listening ear and support.

Support topics include challenging situations, managing tricky relationships, managing difficult feelings, safeguarding support and supporting through loss.



### Contact:

[Barbara.Sujecka@mssociety.org.uk](mailto:Barbara.Sujecka@mssociety.org.uk) or  
[supportwellbeing@mssociety.org.uk](mailto:supportwellbeing@mssociety.org.uk)

# Supporting and Empowering

Our Impact Award for Supporting and Empowering is awarded 'For going the extra mile to support people with MS, helping them to live well and face the future with more confidence'. The three finalists in 2022 were:

## Chris and Anne Todd

Chris and Anne, who both have MS, have been hosting the online meetings for the Hull, Beverley and Holderness Group since the pandemic hit in early 2020. Together, they've hosted endless hours of Zoom calls – doing everything from dance and music sessions to a regular Friday night pub quiz. Sessions can last for up to four hours, but there have been times when they go on all day, such as on Christmas Day 2020.



**Chris said:** "We're surprised and delighted to have won this award. When we started hosting sessions online for the group at the beginning of the pandemic, it helped us all as it was a very frightening time during the lockdowns when we all had to stay at home. The meetings have been so good for us all that we've carried on. Zoom has been amazing to keep us all connected as it's so accessible. There are so many people who have done such amazing things – we feel honoured to have won the award."

Winner!



## Claire Wakefield

Claire joined the North Staffordshire Group as a Support Volunteer in 2020 and became the Group Coordinator a year later. Despite the challenges of the pandemic, she succeeded in recruiting and motivating new volunteer team members. And she led the group in securing funding to launch a number of new services – including wellbeing sessions, social events, crafting sessions and a partnership with Citizens Advice. All these are very well attended and much appreciated by the local MS community. To reach even more people, Claire's also been collaborating on joint projects with a neighbouring group.

**Claire said:** "I was shocked and overwhelmed to be a finalist. I was lost for words, which my team will tell you is quite unusual! When the opportunity came up to do the Group Coordinator role it wasn't something I'd ever considered. I was worried about not being able to do it with everything else going on, but I've enjoyed it so much."

In my whole career I've never received this sort of recognition. I feel really privileged and lucky that I'm able to volunteer with my team – it's the best part of my week."

Finalist

# Supporting and Empowering

## Louise Nicholas

Louise started volunteering with our Welsh project, My MS, My Rights, My Choices. She was then part of the co-production group who developed the ideas behind the follow-on Pontio project and she now sits on its advisory group. She's also a befriending volunteer and supports our work with employers, raising awareness of what it's like to live and work with MS. Louise is committed to ensuring that people with MS have the information they need, when they need it. She's recently been supporting a lady with very advanced MS – helping her to access new technology, signposting her to other assistance and advocating on her behalf.

**Louise said:** "I was pretty amazed to be a finalist, because I don't consider what I do to be that amazing. I've met many volunteers and have seen the amazing things others are doing, and I was very emotional that someone thought I was worthy of being nominated. Because of my symptoms I'm no longer able to drive and work so volunteering gives me something to focus on."



**Finalist**

# Sharing Skills and Expertise

Supporting our volunteers and their managers to develop the skills and expertise needed to carry out their roles is an essential part of the Volunteering Team's work. This support begins as soon as someone sees an advert and chooses to volunteer with us.

## Online recruitment and REACH

Over the last year, the Volunteer Support Team has worked with local groups to support them to follow best practice guidelines when recruiting volunteers locally. We want the experience of joining us to be as seamless as possible. And we want to use a system that removes as much administration as possible from the process of recruiting volunteers.



The REACH platform provides a one-stop shop for all recruitment resources. It also helps to keep potential volunteers updated with the progress of their application through automated updates during the recruitment and induction process.

Volunteers from 12 of our local groups helped us to test the system.

**A volunteer said:** "I used REACH a long time ago and can see that the platform has changed a lot and it is much easier to use now. There's lots of automation and customisation... and I can see it will help manage applications from prospective candidates."

REACH will be launched to volunteers more widely this spring. And we've developed a written guide and an eLearning module to support volunteers to use it. The Social Media

Toolkit on the volunteer website also supports volunteers to boost their skills and confidence to advertise vacancies across social media channels.

## Welcoming volunteers

Our new Welcome Pack has been designed and developed in consultation with volunteers and it includes all the information new starters need to know.

One of the main additions is a new integrated checklist. This contains all the policies and procedures for volunteers in one place. We ask volunteers to complete their checklist and any mandatory training outlined in their role description before they start.

From January, all new volunteers will receive a link to the new Welcome Pack in their Welcome Email. It's also available on the volunteer website: [volunteers.mssociety.org.uk/resources/welcome-pack](https://volunteers.mssociety.org.uk/resources/welcome-pack). Once volunteers have completed their induction, ongoing help is available from their support contact or the Volunteer Support Team.



# Sharing Skills and Expertise

## Welcome Events

Last April, we started running Welcome Events on Zoom for new volunteers. These are an opportunity to meet others and learn more about us and MS, and what support is available to volunteers.



Welcome Events involve videos, presentations and guest speakers, including our CEO Nick Moberly. We're also joined by a volunteer living with MS who's an 'expert by experience'. This provides an opportunity for new volunteers to hear directly about how MS impacts on someone's life.

Volunteers are encouraged to stay afterwards for a coffee and to get to know other volunteers. **One participant said:** "It was amazing to hear about Nikki's journey and the wider charity, and to connect with groups outside of my own."

Welcome Events are open to all volunteers and run on a quarterly basis. Details on how to join one are advertised in our monthly e-newsletter for volunteers.

## Training, troubleshooting sessions and GDPR

We understand how busy our volunteers are and try to make our training as relevant, short and easy to complete as possible. Completing training and staying up to date is an important part of the volunteering role, but we appreciate

that some volunteers may feel less confident than others in completing training online.

In March 2022 we launched our new GDPR Keeping Data Safe eLearning module. This should've been completed by all volunteers who:

- are in roles that handle data (online or on paper)
- have access to our systems (including MSS email)
- haven't completed GDPR training with us in the last two years and need a refresher



More than 1,000 volunteers have received the training so far. Some of our volunteers have supported each other to get it completed, and our Learning and Development Officer is also available to troubleshoot any issues.



**Michelle Bissoo, Data Governance Acting Manager, said:** "We rely on our hard-working volunteers to take good care of the personal information of the people they support. By completing the training, you gain

the knowledge and confidence to keep their information safe.

We know that completing the training is another demand on your time and really appreciate this and your commitment to data safety. We all have to be vigilant with the increased risks of fraud and cybercrime. We hope our tips on spotting these are useful not only here, but in your personal life. Let's continue to work together to protect the personal data entrusted to us."

# Sharing Skills and Expertise

Some volunteers who've been sent this essential new course still need to complete it. Regular support and troubleshooting sessions are available so please get in touch if you need any help.

✉ **Contact:**  
volunteertraining@mssociety.org.uk

## Rethinking reward and recognition

We'd received in feedback from volunteers that our previous efforts to recognise and appreciate their contributions were not reaching everyone. We were therefore keen to review what we could do to improve how we acknowledge and highlight commitment, achievement and success across our volunteering community.

Volunteers and colleagues from across the organisation worked with us to design a new Volunteer Recognition Scheme. We were keen to keep the scheme as simple, accessible and inclusive as possible, and use it to raise awareness of volunteer successes and achievements.

### Recognising length of service

As part of our review, we also wanted to find a way to start recognising how long our volunteers have been with us. So we're now sending out messages on key volunteering anniversaries to thank volunteers for their contribution and ongoing commitment.

### Introducing our Impact Awards

For many years, our Shining Stars programme recognised volunteers for their outstanding contribution. But it wasn't always clear how this linked to key areas of our work. We wanted to consider how volunteer activities contribute to our strategy and how they help us to achieve our mission. So, we worked with a group of volunteers to co-produce our new approach.



We agreed on six key impact areas:

- supporting and empowering
- fundraising
- sharing skills and expertise
- informing
- connecting
- influencing

A judging panel of staff and volunteers was recruited according to diversity of role, geography and background. The panel meets on a quarterly basis to review nominations. Certificates are then awarded to key volunteers to recognise their contributions.

Our panel reviewed more than 150 nominations received since the start of 2020, from our previous Shining Stars programme and for the new Impact Awards. They selected the three most outstanding contributions for each category. These 18 finalists were then invited to join us online for the awards ceremony when the overall winner for each category was revealed.

Our Ambassador, Trishna Bharadia, who's part of the panel, said: "The Impact Awards have been a great way of acknowledging and recognising the valuable contribution that volunteers are making across lots of different aspects of the MS Society's work and the Awards. Having been co-produced and assessed by volunteers means that they're truly 'for us, by us'."

# Sharing Skills and Expertise

I'd encourage anyone who believes that someone's voluntary work with the MS Society should be celebrated to get nominating in 2023!"

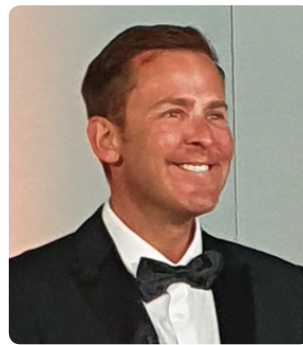
## Awards night

The awards ceremony took place on 5 October. Our Finsbury Park office in London was transformed by lights, cameras and plenty of action. At 7pm our host, DJ Scott Mills, took to the stage, joined by the house band. And former Maccabees stars and Ambassadors, Felix and Hugo White, performed an exclusive, acoustic version of their song 'Silence'.

Our finalists joined us on Zoom, and each award was presented by a celebrity supporter through a pre-recorded video message. A big thank you to Alun Armstrong, Deborah Meaden, Laurence Llewelyn-Bowen, Nicola Walker, Tom Kerridge and Claire King, who all lent their support.

The ceremony was streamed live on Facebook and YouTube, so that our whole community could come together to celebrate. Thanks to everyone who nominated someone for an award and tuned in to join us on the night.

As well as being an important way of thanking our volunteers, the awards have also helped raise the profile of volunteering with us. More than 1,000 people viewed the event online and more than 80 pieces of regional media coverage shared the achievements of MS volunteers. Don't worry if you missed it – you can still watch it on our YouTube channel here: [www.youtube.com/watch?v=BXTKzU-nuhw](http://www.youtube.com/watch?v=BXTKzU-nuhw).



Speaking at the awards ceremony, **Scott Mills**, whose mum is living with MS, said: "The dedication and generosity shown by all of tonight's nominees and winners is nothing short of spectacular.

I know first hand how important community is for people living with MS and it's been heartwarming to hear so many inspiring stories this evening."

If you want to nominate someone for an award, please go to: [www.mssociety.org.uk/get-involved/volunteer/volunteer-impact-awards](http://www.mssociety.org.uk/get-involved/volunteer/volunteer-impact-awards).



# Sharing Skills and Expertise

## Building connections on social media



We understand that volunteers have different experiences of using social media. So, at the end of 2022, we launched a Social Media Toolkit – to support volunteers to use social media effectively to reach and connect with more people affected by MS. This interactive toolkit has been designed in short and digestible sections, so volunteers can dip in and out for guidance on Facebook, Twitter and Instagram.

So far, our Social Media Toolkit has been accessed more than 100 times on the volunteer website: [volunteers.mssociety.org.uk/news/2022/11/supporting-you-social-media](https://volunteers.mssociety.org.uk/news/2022/11/supporting-you-social-media). We hope you find the information and support you need to connect with more people.

## Scotland Wellbeing Hub

Since launching our virtual support to the MS community in May 2020, we've connected with 1,200 people from across Scotland. And we've delivered over 1,500 online sessions, including emotional support through one-to-one counselling, virtual physiotherapy and exercise classes, and peer support. Most people (70%) who access our Wellbeing Hub are new to accessing non-NHS support services.



Participants have reported:

- improvement in their anxiety and depression from accessing the counselling service
- improvement in mood and confidence after participation
- feeling better connected to people with MS

None of this could have been achieved without the ongoing insights from our volunteer Co-production and Advisory Group. They've met with the Wellbeing Hub Team on a regular basis, sharing their thoughts, experiences and insights to help shape our services in the future.



# Sharing Skills and Expertise

**Our Impact Award for Sharing Skills and Expertise is awarded 'For outstanding contributions to the development and delivery of our work. And making sure people living with the effects of MS are at the heart of everything we do'.**

**The three finalists in 2022 were:**

## Robert Oldham

Robert has been volunteering with us in Scotland for over 10 years. Before the pandemic, he delivered face-to-face support programmes. Now, he plays a key role in our Living Well with MS team, helping to facilitate online wellbeing sessions and webinars. With his background in HR, Robert brings expert knowledge about employment, MS and reasonable adjustments – as well as sharing his own experiences.

**On accepting the award Robert said:** "I really wasn't expecting this. I'm delighted and honoured to get this award. I started out volunteering with the MS Society because when I was diagnosed I didn't feel there was enough support and information out there. I felt anything I could do to help other people in the same situation would be for the benefit of everyone."



**Winner!**



## Lorraine Russell

Lorraine has been supporting us since her MS diagnosis at the end of 2020. Despite being newly diagnosed, she joined a co-production group to help shape our Wellbeing Hub – a service that offers support to anyone affected by MS in Scotland. Having benefitted from counselling through the Wellbeing Hub, Lorraine has openly shared her experience with others to help raise awareness of the service.

**Lorraine said:** "Through the work of the Wellbeing Hub, I learned that I wasn't alone and that there was information about MS out there. So, when the opportunity came up to volunteer in the co-production group for the Wellbeing Hub, I immediately saw the benefit. Sharing my experience of counselling at one of the sessions was very personal but I want to demystify it. I want people to feel less alone and empowered to manage their MS."

I was really surprised about being a finalist! I don't volunteer because I want to be rewarded – I find it really rewarding. I already feel recognised and appreciated."

**Finalist**

# Sharing Skills and Expertise

## MS Cymru Cyflawni – Self-Management Project Co-Production Team (Amanda, Hayley Driscoll, Lynne Madden (pictured), Eirlys Ryder, Nikki Flynn, Paul Saurin, Sharon Heir and Val Simmons)



A group of eight volunteers from across Wales came together to explore the best ways to improve self-management skills for people living with MS in Wales. They reviewed evidence from previous work and developed a survey to identify the greatest areas of need and gaps in services. They created a detailed plan, a budget and role descriptions. And they decided how the project would be launched, monitored and evaluated. This project has been pivotal in making sure that people living with MS are at the heart of everything we do in Wales.

**On behalf of the team, Lynne said:** “I feel incredibly proud that our team has reached the finals of the Impact Awards. We worked together so well and I genuinely believe that the combined results of all our ideas, thoughts and experiences should provide a more positive transition for people newly diagnosed with MS. The whole process was thoroughly enjoyable and inspiring and I look forward to another opportunity to volunteer for the MS Society.”

**Finalist**

# Connecting



“Our Regional Forums and listening events have been a great development over the last year. Our Community and Regional Development Officers have worked hard to

help connect and provide information to people living with MS on the support that is available to them. By understanding the local needs of people with MS beyond our local groups, we can help develop solutions that work for the whole MS community – it’s from the community for the community.”

**Abby Caskie**, Regional Development Manager

Over the last year, our Community and Regional Development Officers (RDOs), alongside local volunteers, have delivered a series of Town Halls, regional forums and listening events to understand the needs of local MS communities. At the beginning of 2022, there was understandably still some hesitancy and concern around restarting face-to-face events, and attendance was initially low. But the team continued working hard to reassure volunteers, and to shape and deliver events to meet our community’s needs.

We held a series of information events for people with MS on a variety of topics, including financial security, benefits, working with MS, and keeping physically active. And local experts have joined us to co-deliver these sessions. It’s a really useful way of connecting key organisations and MS professionals to the local MS community. These meetings have also helped us to identify gaps in local need. We’ve supported groups to secure funding, find qualified and experienced service providers, and set up Service Level Agreements and evaluation processes. Any new insight is being used to help us develop new services and activities.

Bringing people together to understand local need and co-produce solutions with them has enabled us to develop more than 50 new local services in England over the past year. It’s also provided us with important insight into the key issues that affect people with MS across the UK.

## North-East counselling project

Volunteers from the Alnwick and District Group, South Northumberland Group and North Tyneside Group collaborated effectively and efficiently to develop a pilot counselling service across their area.

### Identifying the need

The groups initially identified the need for the service by combining forces to carry out research. They used Google and their personal knowledge to find out what was available in their area. They also contacted health care, social care and third sector providers (both locally and nationally) to ask about their current provision.

### Team effort

The three groups met every couple of months to discuss next steps and share out tasks. For example, someone from each group would contact their local organisations and then bring their findings and feedback to the groups. They all contributed ideas and questions for the survey and suggested contacts for potential service providers.

Some group members had personal or professional knowledge to share on certain topics. And there was a lot of healthy and respectful discussions on the talking therapy model that was agreed as the best fit.

# Connecting

## Securing funding

Community Fundraisers took information from the service development plan that the working group had created. They submitted bids to Community Foundation Tyne & Wear and Northumberland, as well as a smaller local trust fund, successfully securing over £3,000 of funding.

## Successful outcome

Nearing the end of the six-month pilot, the counselling service supported five people and had another three on the waiting list. Feedback on the service has been extremely positive. Most 'strongly agree' that they feel more able to manage issues around having MS and more positive about dealing with problems.

**Shelagh Burgess, Administration Volunteer from South Northumberland Group, said:** "It felt good to be part of a team with a very specific and shared goal where people were happy to listen to each other and work through a plan of action collaboratively."

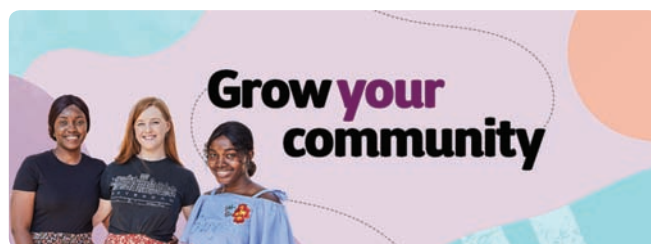
The groups are now looking for further funding to continue the service for at least another 12 months.

## Finding new ways to reach our MS community

This year, we're launching our toolkit and forum to support the MS community to find or create their own communities. By providing an online hub with tools and resources, we aim to bring people together with others that they can truly connect with.

Complementing the invaluable services already offered by our local groups, the hub will be available in the local support section of our website. It's been developed for people not formally involved in one of our local groups

but who'd like to set up their own independent social groups. They can base their social groups around common interests or things that matter to them, such as type of MS or a hobby, so they can connect with like-minded people.



We want this to be a truly empowering resource for the entire MS community, so we've collaborated with other MS organisations on this project. We want to build on our existing community and help it grow, ensuring it's inclusive for everyone.

We hope that, by co-producing resources with members of our community, we'll now have a model that's more attractive to younger people.

**Robby Khullar, a Co-production Volunteer for the project, said:** "This new hub enables people living with (and affected by) MS to build, maintain and promote a support group specifically for their community of interest. Why should anyone face MS alone when collectively, the experience and shoulders of people from our localities are broad enough to support even more people?"

Robby is part of a wonderful team of expert volunteers who have been working together since 2020. The team meets on a fortnightly basis to share their knowledge and expertise, and their insight has been invaluable to make this project a reality.

# Connecting

## External grants

An important part of the Regional Development Team's work is to support groups to develop and extend services – by securing external funding through the National Lottery Community Fund's Awards for All and other restricted funding grants. A great example of this is in Cornwall. Although the county has three active groups, there were significant geographical gaps in services and a lack of volunteers to help run activities.

### Cornwall

Karen, the groups' Regional Development Officer (RDO), set up a meeting with Citizens Advice in Cornwall to discuss the issue and potential solutions. This resulted in a new service that's been created to provide advice on debt, welfare benefits, housing, energy and employment – for people with MS, and their families and carers, in Cornwall. A critical part of this process was the drafting of the Awards for All grant application to secure funding for this new service, and settling on a Service Level Agreement between all those involved.

Deborah Hicks, Communications Volunteer for the South and West Cornwall Group, said: "We're very much looking forward to working with Citizens Advice, which will help the local MS community access a host of services and information. And Citizens Advice can now signpost people who would benefit from our monthly support group meetings, organised range of activities, and financial help through our grant scheme. This partnership is still in its early stages, but we can already see the benefits."



### West Midlands

The Sutton Coldfield and District Group has been running a successful social meet-up for many years. Lyndsay, the RDO, helped the group to conduct an online focus group to find out what other activities the local MS community would like to access in their area. They identified that complementary therapies and exercise would be important additions. With Lyndsay's support, the group applied to a local funder and was successful in securing funding to set up a new reflexology service and group exercise class.

Lyndsay said: "The group worked so hard with me to make these things happen and both of these services have been really successful with 100% positive feedback from our local MS community. It's been great to be able to offer these new activities and to see people coming together to enjoy them."



# Connecting

## Connecting through communication

As well as working with volunteers to extend our community connections, we made some improvements last year to refresh and update our key communication channels.

### Relaunched e-newsletter

Following feedback from volunteers that we needed to streamline our communications, we worked with a small group to review and refresh our e-newsletter. A big thank you to those volunteers who helped shape this work.



Our new format launched in September, providing a monthly update to all our volunteers. It has clear sections for our different volunteers, upcoming events and activities, and practical 'Top Tips' for groups. A new section, featuring profiles of two different volunteers each time, will help us show the breadth and variety of volunteering that's taking place across our organisation. We also want to encourage more engagement through our 'Share your story' form.

We'll continue to publish urgent and immediate news and updates on the volunteer website, so please check it to keep up to date. We're also keen to hear your feedback and content ideas so please get in touch with us.

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

## Volunteer Voice

As the pandemic first hit and we found ourselves in a rapidly changing environment, we needed a way to keep in touch and have a space where our volunteers could voice their concerns and ask questions. As a result, we introduced Volunteer Voice.



As the COVID crisis began to ease, these monthly Zoom sessions remained a great way for our community to come together. In each session, we start with an organisational update from our CEO Nick Moberly and end with a Q&A session on any topics our volunteers would like to raise. During the main part of the meeting, we invite colleagues from different departments to talk about work they're involved in – followed by some lively debates. In 2022, we covered topics such as data security, cost-of-living support and engaging with under-represented groups in our community.

We know that those who attend these sessions find them enjoyable and informative, and that Volunteer Voice is valued as a means to connect with others. However, as we've returned to a more normal way of living, we've seen a steady decrease in attendance as personal commitments and face-to-face activity and fundraising have picked up again. So, last summer, we moved from a monthly to bi-monthly schedule.

We're always keen to hear suggestions for future topics for Volunteer Voice. So if there's a particular issue you'd like us to cover, or an area of our work you'd like to hear more about, do let us know.

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

# Connecting

**Our Impact Award for Connecting is awarded ‘For building networks, creating partnerships, and bringing people together to help make sure no one has to face MS alone’. The three finalists in 2022 were:**

## Thomas Sykes

Tom saved the Mansfield Group from near closure around five years ago. Together with his nephew Ash Sykes, who lives with MS, Tom became Group Coordinator. The group has since flourished and become a place where the young and old across the MS community in Mansfield feel connected.

Tom was the driving force behind the group. He set up an information hub in the local shopping centre for people to access support, have a chat and meet with others living with MS. And he was at the forefront of many fundraising ideas for the group – from tombolas and fairs, to collections at Mansfield Town FC and charity bike rides at the local hospital. During lockdown, Tom’s weekly online quizzes became very popular and kept the MS community connected during this difficult time.

**Tom died unexpectedly early last year. Ash, who was diagnosed with MS in 2012, accepted the award on Tom’s behalf.**

Ash said: “It’s just amazing. Tom wouldn’t be one to accept any recognition for the impact he’s had on people’s lives but he’d be smiling ear to ear. He’s left a big hole in all our lives.”



**Winner!**

# Connecting



## Vicki Brice

Vicki is Group Coordinator of the Sutton Group. When she was diagnosed with MS at age 29, the support of the group pulled her out of “a dark tunnel”. So she decided to use her free time to help others and has volunteered with the group in various roles over the last 10 years. Since becoming Group Coordinator, Vicki is always looking to improve the group and always has people with MS as her focus.

**Vicki said:** “I just love helping people. Supporting people through difficult times and seeing them come out the other side is amazing. I’ve seen how much people can grow with just a little bit of support.

I was honoured to be a finalist. When I found out, I thought someone was having a joke with me! I just do what I have to do, and to be recognised is a shock. But it wouldn’t have been possible without the support of the other volunteers in the Sutton Group, so the Impact Award is for all of them.”

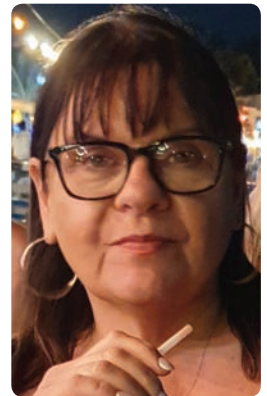
Finalist

## Fiona Salamone

Fiona, who lives with MS, became Group Coordinator of the South and West Cornwall Group in May 2021. The group had been closed for a few years but Fiona brought it back to life by recruiting a strong and talented team of volunteers.

Now, they have over 50 people attending their monthly sessions, which cover many different topics – from fitness to benefits support. Led by Fiona, the group raised over £8,000 last year to be able to host these sessions, and also organise monthly outings – from crazy golf to days out on a yacht. The group has been focusing on building partnerships with local organisations and charities as well as securing funding to ensure people can access the support they need.

**Fiona said:** “I was thrilled and really excited to be finalist. It marks how far we’ve come in a year. Cornwall is so isolated and even though I was on my own at the start it’s amazing to see people come together.”



Finalist



# Informing

Being a trusted source of information is fundamental to who we are and what we do.

Supported by volunteers who so generously share their lived experience, we raise awareness of MS with the public and with decision makers. Through our many channels, from the MS Helpline to events organised by our groups, we ensure that people with MS have the knowledge they need to live well. Within our organisation, we also work to provide our volunteers with the information they need to fulfil their roles confidently and effectively.

## MS Helpline

Our MS Helpline volunteers continued to provide invaluable support to the MS community in 2022. The team includes 21 trained volunteers, who play a key role in providing information, support and signposting over the phone.

In 2022, the MS Helpline responded to 17,258 enquiries.



Volunteers are also central to our Befriending service. Fourteen of them have weekly phone calls with someone who's living with MS. Two of the service users said:

“Talking with another person who has and understands MS is easier than talking with someone who doesn't fully understand. Please give my sincere gratitude and thanks to my volunteer for the time she has given me.”

“Regular calls from someone who had something in common with me broke the cycle of isolation. I'm communicating again and have found my confidence again and am able to laugh and smile. It's just so important to be able to interact with another person. Thank you.”

One of the most popular MS Helpline services is our MS Helpline Nurses (now expanded from two to three). Last year, they responded to 3,378 enquiries. And our MS Benefits Advice Service provided support to 1,464 people with MS. Since this service started in 2019, we estimate that we've gained people with MS over £2,753,000 in new benefits claimed and successful appeals.

We were delighted that our MS Helpline and MS Helpline services were shortlisted for the Helplines Partnership's 'Resilience in the face of adversity' award. This is given to 'an organisation which has managed to deliver a phenomenal service despite being faced with numerous challenges since 2020'.

Such recognition is appreciated, but there are always improvements to be made. Work continues on our Services Transformation Project to link up our regional and national services, making it easier for our community to find and access the support that is right for them. Our volunteers continue to play an important role in taking this work forward.

## Equality, Diversity and Inclusion (EDI)

Our ambition is to make volunteering with us as inclusive as possible, to reflect the true diversity of the MS community and wider society. December marked the one-year anniversary of the launch of our EDI strategy. In this, we committed to a number of actions to help 'recruit and retain a diverse group of volunteers'.



We know that we have a lack of diversity across our volunteer community. To help us understand some of the barriers, last year we met with volunteers from under-represented groups across a variety of roles. We're hugely grateful to those who talked so honestly to us, sharing their perspectives and personal experiences. We're reviewing the issues and recommendations made to form an action plan, which will feed directly into our organisation-wide EDI strategy.

It's critical that we're able to track our progress and engagement with volunteers. We've completed some work to help us understand the effectiveness of our recruitment processes, from when a person decides to apply to volunteer with us, through to when they

decide to leave. This will help us identify any barriers to joining or staying with us.

Another significant development last year was the arrival of our new EDI Programme Manager, Amy Reeve. Amy oversees and coordinates the EDI work across



our teams and works closely with our EDI Reference Group, which is made up of colleagues, volunteers and people living with MS. The group meets on a monthly basis for about an hour. Meetings are an informal, safe space to discuss all things EDI. If you'd like more information, or to join the group, please email us.

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

**Amy said:** "Since starting I've spent a lot of time listening to people's experiences. The MS Society has already achieved a number of actions in its EDI implementation plan. And, although we'd liked to have done more, we've built a good foundation to continue this work this year. I'm keen the voice of our volunteers is carried through everything we do and look forward to meeting more of you over the coming months."

Supporting EDI training will be a big focus for 2023. As well as increasing diversity and ensuring people understand how much we value their time."

To learn about our EDI work please go to: [volunteers.mssociety.org.uk/news/2022/12/we-launch-our-first-equality-diversity-and-inclusion-edi-progress-report](https://volunteers.mssociety.org.uk/news/2022/12/we-launch-our-first-equality-diversity-and-inclusion-edi-progress-report).

## Working in partnership with our Community Networks Advisory Panel (CNAP)

CNAP is a group of volunteers that came together in 2021, to work in partnership with our staff. The Advisory Panel aims to:

- ensure Community Networks groups are represented in strategic discussions about the vital work of our groups
- review volunteer feedback to help identify and prioritise issues that need addressing across our network
- discuss changes to legislation or regulation, or wider changes across the organisation, that might affect the work of our groups and advise on how this is managed
- help ensure that local and central services are delivered in a coordinated and focused way, to meet the needs of the MS community

Last year, the Advisory Panel worked hard to review the group network's ongoing support needs restructuring in 2020, and to shape improvements to address the key issues raised.



“My name is Mike Matulewicz and I’m the co-Chair of CNAP, alongside David Light, Head of Volunteering and Community Networks. We’re a group of volunteers and staff

who meet regularly to advise on the strategic direction of our local networks, and to help them to be most effective in a time when volunteering has become more challenging.

The volunteers on the Panel bring a wealth of experience from their various roles in our groups around the country, and elsewhere in the organisation. Our aim is to further the work of the MS Society locally in times of great change, and strengthen our community networks as we reach out to those affected by MS.”

## Making MS research possible together

Whether it's giving up time to take part in a trial or being a member of our Research Network – many people affected by MS have had an impact on our research this year.

### Octopus trial one step closer to launch



Octopus is a new clinical trial for primary and secondary progressive MS. It's now had the official thumbs up from the regulators, so we hope the trial can begin in early 2023.

Members of our Research Network have been involved in designing this 'mega-trial'. They've helped make sure it meets the needs of people with MS, and helped get us to this crucial milestone.

Lyndsay Shellard, who's been involved since 2019, said: “As Research Network members and people with ‘lived experience’ of MS, our views are very important. We always feel like we're heard and our concerns are valid and taken into consideration. We really feel like we're part of the team delivering Octopus. I feel very privileged to be involved in this project. And hope that in some small way I'm helping find solutions to slow and ultimately stop the progression of MS.”

## UK MS Register celebrates 10<sup>th</sup> birthday

Last year, the UK MS Register celebrated its 10th birthday.

Over 17,000 people have volunteered their time to answer

regular questionnaires about their MS.

This vital data has helped researchers answer key questions about MS, and there's still more it could unlock.



Neil Forbes, who lives with secondary progressive MS, told us how he's participated:

“By getting involved in research I hope I'm facilitating others brainier than me to find a cure. I gave up biology aged 13 – but I can now tell you all about oligodendrocytes!



I was a volunteer when the idea of the UK MS Register was born, and went on to help test the design before it went live. I'm now a volunteer member for the UK MS Register Executive Board. The Board helps make sure the Register is effective, efficient and uses its money wisely.

I'm also someone who still submits my data regularly, like thousands of other people with MS. I hope it'll speed up future discoveries that could help stop MS. I feel optimistic about treatments for progressive MS.”

## Research Network member goes to MS Frontiers

In 2022, our MS Frontiers conference was held in Swansea. It's the UK's biggest MS research conference and brings together scientists, clinicians and healthcare professionals.

Together, they're trying to resolve unanswered questions in MS research.



Rabiah Coon, a member of our Research Network, shared her feedback as a person living with MS at the conference: “The experience of attending and participating in MS Frontiers was priceless. There's so much work being done to improve the lives of those living with MS.

Two things excited me. One was hearing about the strides happening to make research more inclusive and incorporate people of colour who have been excluded until now.

The second is the research into the cause of MS. With that information, one day, MS might be something that merely existed in the past. I have a renewed sense of wanting to keep getting involved in research and encourage others to get involved. I used to hide my MS. It's getting more difficult to do so but still, I'm hopeful.”

**Find out more about how you can join our Research Network on our website:**  
[mssociety.org.uk/research-network](https://mssociety.org.uk/research-network)

# Informing

## MS Awareness Week

MS Awareness Week in 2022 simply wouldn't have been possible without the support of our amazing volunteers. The campaign focused on the uncertainty of the condition and how this impacts on people living with MS.



Staff worked closely with a volunteer focus group of people living with MS to develop the theme and build a wide range of content for media and digital work.

Our volunteer Cherelle – who lives with relapsing MS – spoke on the GB News Breakfast Show, alongside our Executive Director of Research and External Affairs, Dr Sarah Rawlings. Volunteers also helped to raise awareness of MS by sharing their stories across regional radio, print and online platforms, including coverage in Belfast Live, Sunday World, the Glasgow Times, the Daily Record and the Yorkshire Post. A big thank you for your involvement and support.



## Asian MS Webinar

Asian MS offers tailored and culturally-sensitive services for Asian people with MS, their carers, friends and family across the UK. Over the past year, they've worked tirelessly to produce Information Webinars to support people to live well with the condition.

There have been two webinars so far, each attended by more than 60 participants. These sessions will now take place on a quarterly basis, and will help inform the Asian MS community on topics specific to them.



You can find further information on the Asian MS Facebook page here: [www.facebook.com/asianmsuk/](https://www.facebook.com/asianmsuk/) or on our Asian MS webpage here: [www.mssociety.org.uk/care-and-support/emotional-support/national-ms-support-groups/asian-ms](https://www.mssociety.org.uk/care-and-support/emotional-support/national-ms-support-groups/asian-ms)

## Regional Independent Living Centres

Across the country, there are many Independent Living Centres (ILCs), also known as Assisted Living Centres or Disabled Living Centres (DLCs). They are set up in different ways depending on local needs.

Volunteers in our groups in North East England have held numerous meetings in the Newcastle ILC and also visited their adapted equipment centre. The centre is a great source of information and signposting around many aspects of living with various conditions. In 2022, volunteers raised concerns about people living with MS not knowing where to go for relevant information on benefits. As a result, the ILC provided a webinar session on the 'in and out of work benefits' available to people with MS and highlighted local financial support services.

# Informing

Our Impact Award for Informing is awarded 'For showing extraordinary dedication to raising awareness about MS and giving people affected by MS the information they need to live well'. The three finalists in 2022 were:

## Charlotte Hecht

Charlotte has supported the MS Society since being diagnosed with relapsing remitting MS in March 2018. She starred in our Stop MS Appeal launch in 2019, featuring in a national advert and speaking candidly about her experience of becoming a mother when you have MS. Over the last four years, she's continued to raise awareness of MS by speaking and playing the harp at events, and representing us at cheque presentations. She's also cycled 100km and hosted a student concert to raise over £2,000 for us.

**Charlotte said:** "When you're volunteering, you don't expect to reap any benefits. You do it to make a difference and that's all there is to it. It gives me a sense of purpose and I'll keep doing it for as long as I physically can. But winning this means that my contribution has had the positive impact that was intended. And that people value and respect the effort and time I've put into trying to help other people."



## Carla Callaghan

Carla came up with the idea for an 'Ask an Expert' webinar during the height of the pandemic. She'd seen a lot of classes and activities popping up online, but was concerned about the lack of contact with health care professionals. Since her own MS diagnosis, she'd always wanted to help people get the information they need to live well with MS. Carla took the idea to the MS Society Scotland, who turned it into reality by securing funding and launching the new webinars through our Wellbeing Hub.

People from across Scotland can join the themed monthly sessions to hear from a panel of experts, such as physiotherapists, counsellors and nutritionists, and from others with lived experience of MS. Every session, co-hosted by Carla, brings new facts, information and guidance.

**Carla said:** "It was an absolute honour and a surprise to be a finalist. I was thrilled! There are so many people in the community who do so much. Helping other people helps me – it's so rewarding to be able to give something back to the MS community."



## Kirsty Bennett

Kirsty, who lives with relapsing remitting MS, completed one of our self-management courses shortly after her diagnosis at just 21. The advice she received changed her life so much that she wanted to help others with MS in the same way. Now, she volunteers with our Living Well Team, helping to design and run sessions. At these sessions, Kirsty shares hints and tips about the little changes she's made to her life which have made a big difference. She's also spoken about fatigue and returning to work after the pandemic. And she's shared her experience of discussing accessibility adjustments with her employer – giving others the confidence to have similar conversations.

Kirsty's also involved in the Borders Group, where she's been using social media to reach out to younger people. And she was part of a fundraising partnership with a local distillery to develop an MS Society Gin, which raised more than £4,000 for us.

**Kirsty said:** "I don't do it for awards, but I'm really humbled to be a finalist and it means a lot. I've met so many people through volunteering and made some quite good friends. And you learn new techniques for managing your MS from the other people you meet through volunteering."



**Finalist**

# Influencing

Even in more normal times, but particularly in the current climate, we need to campaign on behalf of our community to influence decision makers and ensure everyone can access the treatments, services, care and support they need. Our volunteers help us do this by lending their voices and sharing their experiences to strengthen our campaigning work.

Throughout 2022, we continued to speak out alongside people with MS to demand change. In order to achieve our goal of everyone living well with MS, we're working to improve services and policy across the UK. Last year saw some big campaigning moments for the MS community.

## Breaking Point campaign

In 2022, we faced huge challenges – in particular, a cost-of-living crisis that hit the MS community hard. Nearly a third of people with MS told us they couldn't afford to eat balanced meals, and a similar number were struggling to afford vital medication and treatments. Many were concerned about what the future would bring.

In September, we launched the Breaking Point campaign to call for an immediate support package for people with MS to ensure benefits keep up with rising inflation – and for long-term changes to make sure the benefits system reflects their needs.



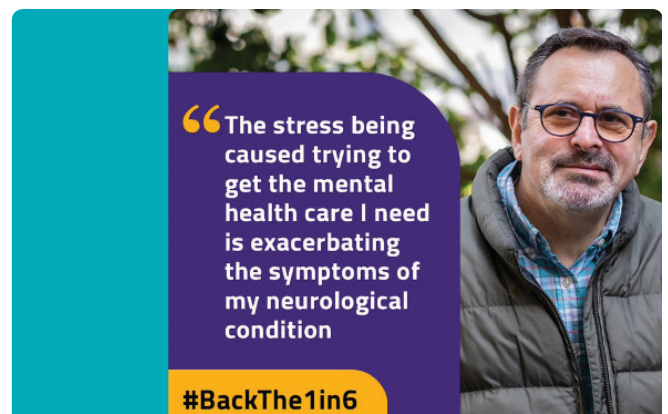
Over 14,000 people signed our petition calling for action, which was handed into 10 Downing Street. People with MS across the country spoke to journalists about their experiences to raise awareness of these important issues, and came to Westminster to speak directly to influential parliamentarians.

The UK Government's financial statement in November brought some positive news. It included a commitment to raise benefits in line with inflation, and the introduction of a new support package for vulnerable people in 2023. While these commitments didn't go as far as we hoped, they were a positive step forward for people with MS to be heard in government. But there's certainly more to come as the campaign grows.

## Back the 1 in 6 campaign

In June, we joined with neurological charities across the UK as part of the Back the 1 in 6 campaign, which called for clinical leadership and real improvements in neurology services. Too many people with MS don't get the care they need and services vary significantly across the UK.

As a united voice, the campaign launched a petition that continues to grow and set out clear recommendations for how to improve neurology services. Calls for action included the establishment of a National Clinical Director





# Influencing

for Neurology to bring together services and provide vital leadership. We were thrilled to hear this role had been secured and we'll go on pushing for improvements in 2023.



## Approved but Denied campaign

Our campaign to improve access to Sativex in England continued in 2022. Sativex is a cannabis-based spray for people with MS who have moderate to severe spasticity. It's used when other treatments haven't worked. Despite being approved for use a few years ago, our 2021 findings showed that less than half of local health bodies in England had Sativex on their approved drugs list. So we called for change.

In 2022, we saw the green shoots of the Approved but Denied campaign. The number of local health bodies who state that they routinely fund Sativex increased by 45%. And we estimate that the number of people receiving Sativex increased by 5%.

We were also excited to hear that Sativex was approved for use by the regulator in Scotland. Something we've been calling for and working on for a long time.

It's a start but we're not letting up, with more plans to push for better access in 2023.

## Tackling concerns on a local level

Volunteers have also been working at a local level to tackle care and service issues. A 'round table' event was held in Cumbria in September. It was attended by group volunteers, members of the MS community, and staff and managers of neurological services at the NHS Trust. The group met to discuss concerns about the loss of their specialist consultant neurologist.



The meeting offered an opportunity for open discussions, where people with MS could express their concerns and give anecdotal evidence. This helped NHS staff to gain invaluable insight into the many issues facing people with MS locally.

Neurological service managers were so impressed by what they learnt, that they've committed to organising regular 'roadshows' to hear more directly from people with MS and other neurological conditions about how their needs can best be met. Commitments have been made to work with the local community and the MS Society on service improvements.

# Influencing

Vanessa Wade and Terri Attwood from the East Cumbria Group said: "Overall, the event provided useful information for us to take back to our local communities. It provided valuable 'orientation' to us as patients, and it gave us voices as people – letting NHS staff see us in person, and listen to us, rather than just as a statistic or name on a bit of paper. It felt like a win-win all around."

## Personal Independence Payments (PIP) in Northern Ireland

Volunteers in Northern Ireland have continued to campaign to improve the benefits system for people living with MS. For a number of years, this has focused on engagement with those who carry out disability assessments, including Personal Independence Payments (PIP).



In an effort to improve the experience of those being assessed, our volunteers have designed and delivered training directly to Disability Assessors. This engagement continued in 2022. And further activity is planned – including running additional training sessions in early 2023 and creating a suite of video testimonies, which will form part of the Disability Assessors' online training. All content and campaign activity are designed and led by our fantastic volunteers.

Volunteer Simon Matchett said: "Lots of us had pretty negative experiences of PIP and assessments the first time around. We wanted to be pragmatic and proactive, so we've been targeting the front line and the decision makers to improve things for the future. By doing so, we're making as great an impact as possible and hopefully increasing understanding of fluctuating and progressive conditions, including MS, along the way. Hopefully it helps lots of people applying for benefits."

## Adult Disability Payment (ADP) in Scotland

As a direct result of the engagement and campaigning work of our volunteers and the MS community, we had some strong campaigning wins last year. These forced the Scottish Government to change its policy. Most notably, it reintroduced indefinite awards as part of the Adult Disability Payment (which replaced PIP in Scotland), ending the need for people to reapply for ADP every few years. As well as this, the Scottish Government committed to reviewing the 20-metre rule. The MS Society and our volunteers have been the loudest voice highlighting the unfairness of this rule. Many have shared with Members of the Scottish Parliament (MSPs) how the rule has impacted on their lives.

## Thank you

None of this would be possible without the thousands of people with MS and their friends and family who join our campaigns. People who share their experiences and demand for action. And those in the community who fight for us all.

Thank you for your support and we'll continue to campaign together until everyone with MS gets the support, services and independence they deserve.

## Volunteers' Week 2022

While we appreciate everything our volunteers do all year round, Volunteers' Week provides the perfect opportunity for us to say a huge thank you. Volunteers' Week runs from 1-7 June, and is an annual celebration of the contribution millions of people make to causes across the UK, through volunteering.

And we believe that you, our volunteers, are the best of the best! We were created by volunteers in 1953, and our volunteers are involved in all areas of the organisation.

As part of our thank you, and to inspire others to join us, we ran a series of blogposts across the week from our community about their experiences of volunteering with us. These were published on our website and shared across our social media channels. And we weren't the only ones who enjoyed reading your stories.



Our engagement rate on Facebook almost doubled during Volunteers' Week last year compared to 2021. On Twitter, we saw more than double the engagement for the highest performing post, which was the story of Paul and Sue from the Isle of Wight Group receiving the Queen's Award for Voluntary Service at Buckingham Palace.

We hope the spotlight of Volunteers' Week 2022 made you feel proud to be part of a team that makes such a difference to people living with MS. [volunteers.mssociety.org.uk/news/2022/06/volunteers-week-message-nick-moberly](https://volunteers.mssociety.org.uk/news/2022/06/volunteers-week-message-nick-moberly)

# Influencing

**Our Impact Award for Influencing is awarded 'For speaking up for the MS community, and bringing about change at local or national level'.  
The three finalists in 2022 were:**

## Simon Hoare MP

Simon Hoare, MP for North Dorset, has been the Chair of the All-Party Parliamentary Group (APPG) for Multiple Sclerosis since 2016. As Chair, he's championed the MS Society in Parliament and his local constituency. He's supported our campaigns on access to treatments, better employment and improving neurology services. And he's continually raised the profile of MS in the House of Commons.

On accepting the award, Simon said: "It's a huge honour and I accept it very humbly on behalf of all my parliamentary colleagues who have worked to support the APPG for MS, my office staff and of course the amazing team at the MS Society who make it all work so seamlessly. Hopefully we've made a difference and those of us in Parliament with an interest in MS will continue to make a difference. Thank you so much."



**Winner!**



## Amy Sutherland

Amy is Group Coordinator of the Fife Group. She was diagnosed with relapsing remitting MS when she was 34. Her volunteering contributions include creating a cinema pass scheme for young carers, arranging burlesque chair dancing classes for Fife Group members, and raising money for a beach wheelchair. One of her highlights is developing an 'MS Kit' to help others understand what it can be like to live with the condition. Users wear arm and leg weights and gloves and goggles, to replicate MS symptoms and then try (and struggle) to carry out everyday tasks. Amy's used the kit with doctors and medical students, and even an MSP.

Amy said: "I was shocked and quite taken aback when I heard I was a finalist. I didn't believe it at first. The thing you've got to remember is that this is a team event. I didn't do all this on my own. It's a team effort, I'm just the mouth! It's nice to get a bit of recognition, but at the end of the day that's not why we do it."

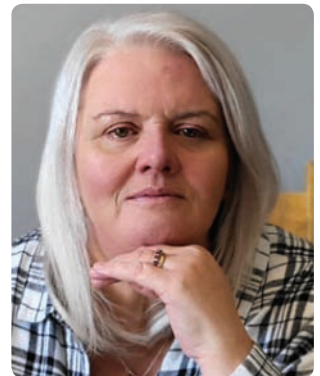
**Finalist**

# Influencing

## Lynne Roberts

Lynne Roberts was Group Coordinator of the Moray Group for five years until 2022. The group was on the verge of closing, but Lynne gave it a new lease of life. She led the group to develop and fund services (exercise and physiotherapy, and one-to-one counselling) that were desperately needed in the area. And she found new ways to engage with the MS community – by getting the group onto social media to advertise their events, and developing an eye-catching poster for display in health settings around Moray. She was always looking to raise awareness of MS wherever she could. She also met with her local MSP and other representatives from neurological groups to look at local service and support provision.

**Lynne said:** “It was very humbling to learn I was shortlisted for the award amongst so many deserving others. I was surprised to say the least! Had it not been for the dedicated volunteer team and the fabulous support of the people of Moray, much of what was achieved couldn't have been. These awards also help publicise the opportunities of volunteering, which in turn extends the reach to help more people living with MS.”



**Finalist**

# Fundraising

With in-person fundraising events back on in 2022, there were many new and inspiring stories of our supporters volunteering their time and efforts to help us Stop MS. A huge thank you to everyone who's raised money for us. You can find a snapshot from across the country below.

Another big thank you also goes to all our groups that supported fundraisers undertaking long-distance challenges across the UK. Volunteers turning up (often at short notice) in all kinds of weather to provide a warm welcome at stop off points – waving flags and banners, sharing a meal or sorting out a B&B – really boost a fundraiser's morale!

## England

Stuart Dawson, aged 63, set his sights on completing a 600-mile walking tour of English Premier League football stadiums. He wanted to raise a whopping £20,000 for our Stop MS Appeal after seeing the impact the condition had on a close friend.



A number of Stuart's family and friends have MS, including his good friend Nick, who he first met when they played for rival football teams. Nick was diagnosed with progressive MS in 2014 and his mobility has since deteriorated. In 2020, Nick was advised about a medication that would help with his condition but the

Clinical Commissioning Group was unable to fund the treatment. Nick believes that, if he lived in a neighbouring county, the cost of the treatment would be funded.

Stuart's target of £20,000 is equivalent to the estimated cost of funding Nick's treatment for a year.

The challenge (starting in Newcastle and ending in Bournemouth) took Stuart 24 days to complete. He's already raised £15,920 and still has several items to auction off that were donated to him by the clubs he visited on his journey.

He hopes to have raised awareness not only of Nick's situation, but also of our Stop MS Appeal and the mental and physical health benefits of Walking Football.

## Northern Ireland



Siobhan Allister, Group Coordinator of the Fermanagh Group in Northern Ireland, organised a 'Walk, Stroll or Run for Fermanagh MS Group' event. It was designed

so that people of all abilities, including wheelchair users, could take part. The event attracted fantastic support – with 320 participants walking, strolling or running through the grounds of Irvinestown's Necarne Castle. An incredible £3,020 was raised for the local MS group.

**Siobhan said:** "It was really hard work organising the day, but when I saw the sea of orange MS Society T-shirts walking off it was so rewarding. People in the town were talking about it for days. We not only had a great day and raised vital funds in support of local services to the MS community, but we raised awareness of MS in the wider community too."

# Fundraising

As well as being a local Group Coordinator, Siobhan is a member of our National Council for Northern Ireland. She brings to this role a wealth of insights as a person living with MS, and years of experience of working in a local group. She'd set herself a personal target to raise £10,000 in 2022 but managed over £11,000 – adding to the many thousands she's already raised for the MS community over the years.

## Scotland

Last August, 24 members of the Bearsden Martial Arts Club took part in a martial arts marathon for MS Society Scotland.



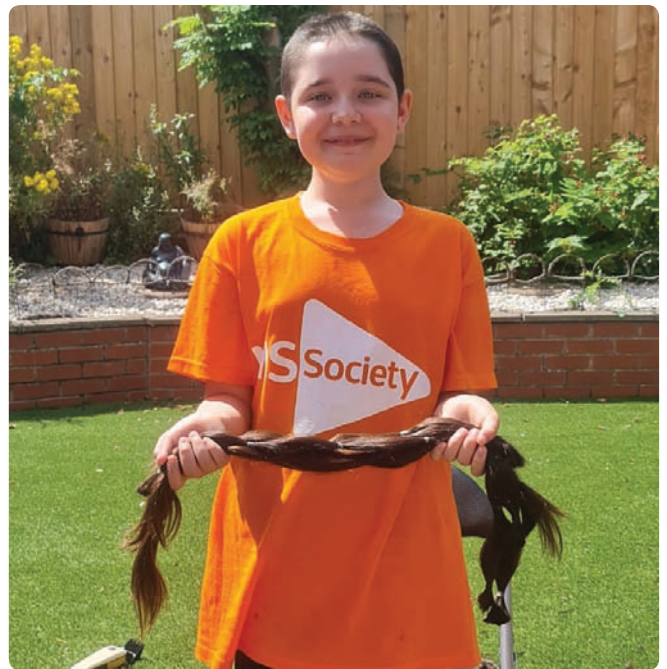
Their members either have MS or have family members with MS. Martial arts training has helped with balance, coordination and fitness, as a way to recover from MS incidents.

The day included nine hours of martial arts, involving everyone in the club from juniors to seniors. Even parents got involved on the mats.

The day raised an amazing £2,622 for us – although there were a lot of sore bodies at the end of it.

## Wales

Ten-year-old Maisey lives in South Wales. A close family member had been diagnosed with MS, and struggled through the pandemic to get appointments. When Maisey found out there was no cure for MS, she decided to help out by fundraising.



Maisey wanted Rapunzel hair and had never let her mum cut more than two inches off. So it came as a big shock to the family when she decided to shave it off to raise money for us. Her original goal was to raise £100, but her mum persuaded her to try for £250 and they set up a JustGiving page. Word got out about Maisey's wonderful fundraiser and she even got a video of support from the actor Michael Sheen, as she's a big fan of Good Omens.

Maisey raised an incredible £1,510. She also donated around 20 inches of her hair to the Little Princess Trust, a charity that makes and provides real hair wigs for free to young people with illness.

Thanks so much to Maisey and her family for all their support. Diolch yn fawr iawn pawb!

# Fundraising

## Shops



An important source of income comes from our shops. We have six across the country. Each has a paid manager, but they couldn't keep running without the time and dedication so generously given by volunteers.

In 2020, our Isle of Wight shop had its best year ever – turning over around £120,000! Of that, £25,000 has already been donated to our Stop MS Appeal. The shop's profits also help fund a range of services and activities for those on the island living with MS. This includes therapy from two dedicated MS nurses as well as days out and evening events – helping those who may be struggling financially. And the local group's always on hand to inform, advise and support when needed. The positive impact is kindness and care for all.

**Shop Manager, Lynda, said:** “We have a strong team of 24 volunteers here. Each one is highly valued and appreciated for all the time and commitment they give us.

I'm truly honoured to have such a great team behind me and very lucky to be able to call them all my friends. The volunteers love their roles within the shop and at events. It gives them confidence and a sense of achievement.”

## BBC Lifeline Appeal

Last June, we had a BBC Lifeline TV Appeal broadcast on BBC One. It was an amazing opportunity to let people know more about what it's like to live with MS and what we do to help.

The appeal raised more than £13,000 through kind donations from viewers.

What made it work so well was the personal stories we were able to share. We're incredibly grateful to the volunteers who gave their time for filming and who were willing to talk so openly about the impact MS has on them.

Sasha, a mum of three from Birmingham, talked about being diagnosed with MS just weeks after the birth of her youngest child. She's received support from our MS Helpline. Stuart and his family, who live in County Durham, spoke about the impact of our research. He said: “Family and friends said it was such a great piece, very powerful, well balanced, and gave a lot of positivity. Some said they hadn't realised exactly what we go through living with MS and that it's been very insightful.”

Val, Group Coordinator of our Conwy and North Denbighshire Group, appeared in the appeal. Val said: “We were delighted when the BBC asked us if they could film at our group. It was a privilege. I was nervous to see the film, but thought it was very good...the way it focused on the experiences of different people.





# Fundraising

I know what all of them are going through. Straight after the broadcast I was getting lots of phone calls and messages. Everyone was so pleased! The film has been great at raising awareness and money.”

The Michelin-starred chef, Tom Kerridge, gave his time for free to present the appeal and spent a day filming with us. He also shared the story of how MS affected his dad, enabling us to spread news of the appeal more widely in blogs and local media coverage.

## Enthuse

We're always looking for new ways to support our volunteers with the challenges of fundraising. In 2022, we started looking for a new fundraising platform for our groups to use. Some were already using other platforms such as JustGiving. But funds from these have to be paid into our central bank account and then distributed to groups, causing complexity and delays. Enthuse were able to offer us both cheaper rates and the functionality for donations to be paid monthly directly into each group's own account.

We worked with Enthuse to set up branded fundraising pages for our groups to personalise and use. And we ran a pilot programme with some of these groups, who tested everything out and provided valuable feedback.

Once any issues had been resolved, we securely registered the bank details of all our groups, so that those wishing to use it could do so quickly and easily. We also offered Zoom sessions where groups could find out more and ask any questions.



### What does Enthuse offer?

- People can donate directly to your group on Enthuse, through one-off or regular donations
- Supporters doing events to raise money for your group can set up their own fundraising pages on Enthuse
- People can create teams on Enthuse to fundraise together
- You can sell tickets for group events on Enthuse, so you don't need to collect cash or use paper forms (more information on this will be released later)

At the time of writing, 17 groups have attended training sessions, and 24 have signed up to use Enthuse. The Basingstoke and District Group, which was part of our pilot programme, has already raised over £1,500, which is going directly into their bank account. You can check out their page here – [msgroups.enthuse.com/basingstokedistrict/profile](https://msgroups.enthuse.com/basingstokedistrict/profile).

### Find out more

If you'd like to know more, you can find all of the information on the volunteer website by searching for 'Enthuse'. Page set-up fees have been paid centrally, so there's no direct cost to local groups. Simply complete the form here – [tinyurl.com/2u9azw2k](https://tinyurl.com/2u9azw2k) – and our Fundraising Team will be able to set you up to create your own page and start fundraising on it.

# Fundraising

**Our Impact Award for Fundraising is awarded 'For inspiring efforts to raise money for us, helping us get closer to our vision of a world free from the effects of MS'. The three finalists in 2022 were:**

## Gareth Reynolds

In late 2020 and early 2021, Gareth took on a solo row of 3000 miles across the Atlantic as part of the Talisker Whisky Atlantic Challenge. Starting in the Canary Islands and ending in Antigua, this challenge is billed as 'the world's toughest row'. Gareth had previously sailed the Atlantic with family members. But this was a challenge that would push him to his limits – both physically and mentally. He rowed over 1.5 million strokes for up to 20 hours a day, sleeping only in short bursts. He had to battle not only the perilous conditions of the ocean (waves over 20ft high, extreme weather, sharks, shipping lanes) but also the isolation of knowing that any outside help was days away.

Gareth completed his amazing journey in 51 days, 3 hours and 59 minutes – raising over £70,000 for us and becoming a local hero. He continues to support our MS communities in Wales, attending events and inspiring others.

**Gareth said:** "Thank you so much. It was just an honour to be nominated so to win is very humbling. It was a huge team effort all around to complete the challenge and I couldn't have done it without everyone involved."



**Winner!**



## Mary's Snowflake Creations – Catherine (pictured) and Chris Heaton, and Winnie Barrett

Mary's Snowflake Creations was founded by Catherine – who lives with MS – in 2014. Having been medically retired from her career, she wanted to put her time to good use, so that something positive could come from her diagnosis. Along with friend Winnie, and supported by a wider team of volunteers, Catherine fulfils requests for all manner of hand-knitted and crocheted items. Husband Chris takes charge of admin and logistics.

Customers are charged only for the materials used – and asked to donate to us instead for the time and labour spent on each item. To date they've raised £12,000, while increasing awareness of MS and showing how you can still enjoy your passions in life – such as knitting!

**Catherine said:** “Being a finalist really blew me away. The whole team works really hard, so this was a wonderful and unexpected validation of all our efforts.

For me, it's all about raising money that will go directly towards medical trials and research. I want future generations to speak of MS as something which existed 'in the olden days'.”

**Finalist**

## Liam Waddington

Liam Waddington, also known as Vizeh, has raised over £17,000 for the MS Society.

Liam's mother died of MS complications in 2013 when he was a teenager. One of the ways he coped was by making gaming videos to share online. Now, he's a well-known football and FIFA YouTuber with hundreds of thousands of subscribers worldwide.

He uses his social media platform to fundraise by completing marathon challenges online. One was a 50-hour live stream, where he did everything from eating a ghost chilli pepper to shaving his head. And, in 2021, he completed an intense superhero-inspired physical challenge – by doing 100 sit ups, 100 push ups, 100 squats and a 10km run every day for a month. All in memory of his mother.

Liam also uses his platform to raise awareness of MS and the work of the MS Society. He's determined to stop MS and make life better for those affected by it.

**Finalist**

# Contacts

## Our offices

### MS Society

Carriage House,  
8 City North Place,  
London N4 3FU  
0300 500 8084

### MS Society Cymru

Clockwise@Brunel House,  
2 Fitzalan Road,  
Cardiff CF24 0EB  
0208 438 0700

### MS Society

#### Northern Ireland

The Resource Centre  
34 Annadale Avenue  
Belfast BT7 3JJ  
02890 802 802

### MS Society Scotland

gyleWorks,  
34 South Gyle Crescent,  
Edinburgh EH12 9EB  
0131 335 4050



## Volunteering contacts

### For day-to-day support:

- Local groups -  
✉ [volunteersupport@mssociety.org.uk](mailto:volunteersupport@mssociety.org.uk)  
or 0300 500 8084, option #3
- Non-group volunteers -  
email your designated staff contact

### For information or feedback on volunteer communications:

✉ [volunteercomms@mssociety.org.uk](mailto:volunteercomms@mssociety.org.uk)

### For help and support with volunteer training:

✉ [volunteer.training@mssociety.org.uk](mailto:volunteer.training@mssociety.org.uk)

## 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)

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

### National MS Helpline

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