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May 2019

Teamspirit



Stop MS

The public phase of our Stop MS appeal is launching in the next few months and will be the biggest campaign the MS Society has ever launched. We're all coming together to Stop MS, whether volunteers, donors, members, scientists or members of staff.

All of us, have a role to play!

Decades of research have got us to a critical point. We finally know what to do to stop MS, and we need to act now. Our Stop MS appeal aims to raise £100 million to fund pioneering new research. By 2025, we believe we can find treatments for everyone with MS.





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

Stop MS continued

So how can you get involved?

We can all play a part in stopping MS, but how you get involved is up to you! At the spring forums you'll have been given information about the appeal, including a menu of ways you can get involved depending on how much time your local group volunteers have. This provides ideas for raising awareness of the appeal and playing a part in raising £100 million by 2024 to stop MS in it's tracks. If you were unable to attend one of the forums, the menu of ways to get involved will be made available on the volunteering website from early in May, along with lots of other resources. There'll also be information about the aims of the appeal, including the clinical trials platform and the research which will be funded.

Contact: Campaigns team campaigns@mssociety.org.uk

Spring Appeal

Our Spring appeal arrived with over 50,000 supporters on April 27 focussing on research by Professor David Lyons and his team in Edinburgh who are using zebrafish to understand myelin formation. The appeal mailing includes a letter from Professor Lyons and a booklet about his research.

A reminder mailing will be going out to supporters in the next few weeks, which will come from our new CEO Nick Moberly and



include copies of images of the zebrafish. We're hoping to raise around £150,000 for MS research.

If you would like any further information then get in touch.

Contact: Molly Amson Knight, Direct Marketing Officer molly.amson.knight@mssociety.org.uk

Save the date – Cake Break 2019!

Cake Break is back, and this year it's bigger than ever! TV cheffing duo the Hairy Bikers are backing the campaign, and calling on everyone to host a Cake Break on October 4 – the official date of Cake Break 2019.

You can register now to receive your free fundraising pack, containing all the bits and bobs you need to make your Cake Break a success, plus some flan-tastic recipes from Hairy Bikers Dave and Si as an extra treat.

We're inviting everyone to join in on 4 October, but if another date suits you better than you can take yours whenever you like.

For more information and to register head to the website here: cakebreak.org.uk

Contact: Cakebreak team cakebreak@mssociety.org.uk 0300 500 8084



Strategy matters: get involved!

In March we told you about our current work on developing our 2020-2024 strategy – building on the success of the last five years and guiding our work and decision making through the next five years.

Whatever your role, you're the experts – so tell us what you think.

We want to speak to your group volunteers and members about what we've achieved so far and get your opinion on successes, challenges and opportunities, to help us develop a strong strategy.

Please take a few minutes and tell us what you think here: tiny.cc/strategy2024

Your views, experience and practical knowledge of MS and the MS Society, along with all the feedback we receive, will all help make sure we're focusing on the right things.

Where have we got to so far?

Based on views from volunteers and staff, we've come up with some basic principles to work from and some further questions to ask:



Our mission and vision still clearly say what we want to achieve. How can we build on our achievements of the last five years?



Our goals still stand but should we look at them again to help us focus our resources on greater achievements?



We need to adapt and respond to a rapidly changing world. What big or small changes have you noticed that we need to react to or prepare for?



Everyone has different needs. How can we make sure we are able to reach out and tailor what we do across the MS community?



We mustn't be afraid of change. How can we work differently to better achieve our vision, mission and goals?

There is still time to get involved with focus groups which will be held across the UK in May. We want to ensure that people living with MS have the opportunity to give their views on the way forward for 2020/24.

If you have any questions, have something to say about the strategy or would like to be involved in the focus groups then please email the strategy team.

Finally, a big thank you for your contributions so far, please pass on these messages to anyone you think would be interested but might not get Teamspirit.

Contact: Strategy team strategy2024@mssociety.org.uk

Want to share your group's good news?

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



Celebrate Volunteers' Week with us this year

Volunteers' Week is a national celebration of everything that's great about volunteering. From 1-7 June, UK organisations will be talking about the impact of their volunteers. We believe our volunteers are the best of the best, and we want everyone to know!

We'll be shouting about our volunteers across our social media channels and websites by sharing case studies, blogs and articles about volunteer experiences and opportunities to volunteer with us. And we'll be telling everyone about our inspirational Shining Stars and the massive role you all play in working to stop MS.

We'd love you to join in with our Volunteers' Week celebrations, here are some ideas you could try:

- Organise a celebration acknowledging your achievements and thanking your team of volunteers
- Nominate volunteers for Shining Star awards

 if you're quick we'll try to get the award to
 you in time for Volunteers' Week
- Get your local press involved
- Take pictures or make a video of your groups celebrations, or an interview talking about your achievements and upload this to social media using #VolunteersWeek

You'll find everything you need on our volunteer website, search for:

- Shining star nominations
- Organising events
- Press and publicity
- Online promotion

If you have any questions, please get in touch. We hope you have a fantastic Volunteers' Week!

Contact: Volunteering team volunteering@mssociety.org.uk

Raising our voice to #ScrapPIP20m

Last year, over 36,000 of us signed a petition telling the UK Government to scrap the PIP 20 metre rule. Thanks to your support, the Government has been talking to us about some ways they can make PIP better for people with MS. But they haven't scrapped the rule and we won't stop till they do.

Recent research

We know the 20 metre rule is failing people with MS. We found that the 20 metre rule is also predicted to cost the UK Government millions more than it saves by cutting PIP payments. This year, the Government are reviewing their spending and will be deciding how to spend money over the next few years. So we decided to take action.

Raising our voice

Last month, over 8000 of us wrote to Amber Rudd MP, Work and Pensions Secretary, asking her to scrap the 20 metre rule – that's more emails to an MP than we've ever sent before! Together, we said 20 metre rule simply doesn't make sense – for people with MS or the Government.

As the UK Government reviews their spending over the coming months, we'll be continuing to call for the 20 metre rule to be scrapped.

To keep up to date on the campaign, join our Campaigns Community here: tinyurl.com/y3ra4uqd

Contact: Campaigns team campaigns@mssociety.org.uk



Cannabis for MS Campaign

In November 2018, cannabis for medicinal use was legalised. But, while the change in law means specialists can now prescribe cannabis-based medicinal products in certain circumstances, we're concerned that the temporary guidance is putting specialists off from prescribing it. We're hearing from more and more people with MS who are being denied cannabis for medicinal use. This needs to change.

Speaking up

In March, we took our campaign to Westminster and Genevieve Edwards, our Director of External Affairs, gave evidence to a committee of MPs looking at the new system.

She called on the UK Government to take this issue seriously and highlighted that people with MS continue to be denied a treatment option that could help with pain and spasticity.

New guidance for clinicians is due to be issued in October and Genevieve called for it to include evidence that cannabis for medicinal use can help people with MS.

She also called on the Government to create a plan to tackle the current challenges with cannabis for medicinal use and ensure that people can get the treatments they need.

Are you speaking to your GP or neurologist about medicinal cannabis? You could help us understand what the new law means for people living with MS. Please tell us about your experiences.

Contact: Campaigns team campaigns@mssociety.org.uk

MS family & friends

Family and friends play a vitally important role enabling people with Multiple Sclerosis (MS) to live well.

We want to provide information and services that will help those who support people with MS. We want to campaign about the things that matter to them.

If you're a carer, friend or family member of someone living with MS, we want to hear about your experiences.

What you tell us will drive improvements in our support as well as helping to strengthen our campaigns, focusing where you tell us improvement is most needed across the health, social care, welfare systems and beyond.

We know family and friends supporting people with MS face multiple challenges across the UK and too often do not get the support they need. We will use the results of this survey to tackle these challenges head on.

This survey is available online only until May 31, fill out the survey here: tinyurl.com/ms-family-friends

We'd love to hear from as many people as possible across the UK, so that we can ensure the results are as accurate and representative as possible. Please spread the word far and wide.

Thank you for helping us to reach as many people as possible!

Contact: Brooke Lumicisi, Evidence Manager evidence@mssociety.org.uk



Key updates and information to help run your group.

New and updated resources from the Information Resources Team

'How we can help you'

People with MS and health professionals working with them have told us that it would be good to have all our key information in one handy place. So we've created a new credit card sized, fold out leaflet. It provides information on services such as how to apply for a grant, contact the helpline, order booklets or download factsheets. You will also find information on volunteering, our online community and how to find a group near you. Order from the online shop, using the code CC04.

'MS and your bladder'

A new booklet called 'MS and your bladder', has been created to replace essential 07 'Managing bladder problems'. Up to 8 in 10 people with MS will have bladder issues at some point. This new booklet looks at how MS can affect the bladder, established and emerging treatments, professionals who can help, plus lots of useful tips. The booklet has an introduction from Catherine, who has MS-related bladder issues. Code BK30.

'Just diagnosed' booklet – Welsh/English version

This key publication has been updated. Among the changes are mentions of HSCT and ocrelizumab, plus more on smoking, and a new cover. Order code for this bilingual booklet remains the same (BK24 WE).

Order your booklets now

All of these printed publications are available from the online shop to order your free copies visit the shop: mss.ecgroup.net/login and create a group account. You must use your group MS Society email address to register an account, personal emails will not be allowed. Please remove from circulation copies of the old publications that these updated titles replace.

Contact: Online shop team shop@mssociety.org.uk 020 8438 0999

Information for your group



New web pages

Sativex

As part of our new information on cannabisbased medicines, we now have a web page about the spasticity drug Sativex. It explains how well it might work for some people with muscle stiffness and spasms, possible side effects, and it's very restricted availability across the UK outside of Wales.

It also clears up how last year's change in the law on medicinal cannabis doesn't make Sativex any easier to get. Find this page here: mssociety.org.uk/sativex

Talking to your health care professionals about medicinal cannabis

Following the 2018 change in the law on medicinal cannabis, there's been confusion over what the situation now is – among medical professionals and people with MS. This web page explains when it might be worth mentioning this subject with your health care professionals and how difficult it is to get a prescription for cannabis-based products.

It also clears up common misconceptions around this issue. If you bring this up and you're not happy with the response you get, there's information on what to do next. You'll find the page here: mssociety.org.uk/talking-aboutmedicinal-cannabis

Contact: Supporter Care team supportercare@mssociety.org.uk 0300 500 8084



Latest volunteer resources, training and support.

Help us to improve how we support our local groups

In the March edition of Teamspirit we told you that we want to improve the support we offer to our local groups. We're grateful to the volunteers who have come forward to take part in a reference group to lead this work.

This summer we'll be holding a number of events across the UK inviting a wider selection of volunteers to tell us what is working well about the support you receive to help you do your role, and to identify the areas which could be improved. Please look out for these events on our volunteer website.

If you're not able to attend any of these events, please complete the volunteer survey which will also be sent in summer for an opportunity to have your say.

In the autumn we'll reflect on what volunteers have been telling us and will share some thoughts and ideas on how we could improve.

Please get in touch for more information about this work.

Contact: David Light david.light@mssociety.org.uk

One year on: General Data Protection Regulation (GDPR)

GDPR is now one year old. In that year a lot has changed but hopefully with minimum disruption so you didn't notice the tightening up of processes, making sure we're all compliant. That way we avoid negative press or worse, fines which means less money going to vital research.

That's where you come in

We've asked for certain volunteers to complete the GDPR e-learning 'Data Essentials', and need to do so by the end of May 2019. This is your chance to do so if you haven't yet!

Anyone handling personal information must be trained to understand their responsibilities around that data. We must be able to prove this understanding if asked by the regulators. We all have a responsibility as part of the MS Society to keep our own and everyone's data safe and secure by following the guidelines, policies and processes in place. Here's a list of three things that you can do now:

- Complete the GDPR e-learning
- Keep up to date with the Group Handbook, specifically Section 6: Handling Data. This tells you what to do if there's a breach, how to keep data secure and lots of other useful tips.
- Contact the Data Governance team or your LNO if you need further guidance.

Contact: Data governance team datagovernance@mssociety.org.uk

Support for volunteers



Refresher training for transport volunteers

All transport volunteers whether drivers, passenger assistants or individuals who manage servicing and maintenance, are involved in the safe and effective running of the group vehicle.

We give all transport volunteers an overall view of how the vehicle can be operated safely through completing of an initial induction that also gives specific information relevant to their role.

We also needs all transport volunteers to complete refresher training every three years (recommended by the Health and Safety Executive) to make sure that if there have been any changes to the vehicles, group or individual these are taken into account.

Why do we need to do this?

Completing health and safety training specific to your vehicle helps you to:

- Make sure you know how to work safely and without risks to health
- Develop a positive health and safety culture, where safe and healthy working becomes second nature to everyone
- Meet your legal duty as one of our volunteers, to protect the health and safety of passengers, other volunteers, members, employees and anyone else who may be affected by our activities

Following the 2018 transport audits we received feedback from the groups requesting a review and update to the existing induction form.

This has now been completed and can be found on the volunteer website here: volunteers. mssociety.org.uk/transport-risk-system

MS Society emails upgrade – project update

Now is the time to upgrade your group's MS Society email.

You'll have heard about the MS Society email upgrade, which we have been offering to groups since August 2018. The range of email tools the upgrade gives your group access to includes: password self-reset, shared file storage, shared calendar, mobile and tablet access.

Following our offer of this upgrade last year, it is now compulsory that all groups migrate to ensure we are able to meet our GDPR (General Data Protection Regulation) requirements. If your group continues to share log-in details to your current group inbox by sharing user names and passwords; you are breaking this regulation and risk making personal data insecure, causing a data breach.

Over half of our groups have already upgraded, or are in the process of upgrading, their email accounts. The process is very straightforward and our Volunteering team are here to support you so that you get through it as quickly and efficiently as possible.

For more information, visit the volunteer website here: volunteers.mssociety.org.uk/ news/2018/08/ms-society-email-upgrade If your group has not started the upgrade process, please contact us now so you are not left behind, and you are not in breach of the GDPR.

If you have further questions about MS Society email, please contact us.

Contact: Volunteering team volunteering@mssociety.org.uk

Contact: Your local LNO

Support for volunteers



Just giving

It's great that we're seeing local supporters setting up online sponsorship pages with providers such as JustGiving to raise money for local groups. It isn't always clear though, so some of the donations have gone to general funds rather than being transferred to your group to use locally.

To make sure we return funds to your group account quickly, please ask any supporters to include the name of your group and that they are fundraising for you on their online giving page.

You or the supporter should then contact the Supporter Care team to confirm the supporter's details.

This will make sure that all the funds raised, including any Gift Aid, are transferred to the group on a monthly basis.

Please do encourage your local fundraisers to use online giving sites such as JustGiving. The fees for using these online pages are currently paid centrally and not by the group so it's a really efficient way for you to raise money.

To find out more about this get in touch.

Contact: Your local Area Fundraiser



Finance



Monitoring group income – Online Accounting Events

Did you know that you can monitor group income for a particular event? Within Online Accounting the event function lets you monitor income (and expenditure) for a specified event and time scale. Here is a quick setup guide:-

- Firstly, the event will need to be setup within the events tab. Your Finance volunteers will need to complete this, due to their admin rights. To add an event simply select 'Add new record' and enter the details of the event – a start date must be provided.
- 2. Time to analyse! You are now able to allocate income and expenditure to this event. In order to attach a deposit/expense to a specific event, select the event from the drop down menu within the transaction analysis screen.

Within the report section you can now run two types of reports for specified events and date ranges:-

- Receipts and Payments providing overall totals
- Transaction reports lists all transaction analysed to an event

Many groups find the event monitoring helpful for their planning and budgeting. Examples of common events are exercise classes, specified collections, fundraising events and Christmas parties.

Please don't hesitate to contact the Finance Team if you would like to discuss setting up an event within Online Accounting.

Contact: Finance support team **financesupport@mssociety.org.uk**

Operating in financial safety

Our trustees are ultimately responsible for all funds. To make sure funds are raised, used and held in accordance with good practice and various regulations, trustees have put in place financial rules (Appendix four of the Group Handbook).

All coordinating team volunteers need to be aware of these rules – not just the finance volunteer.

We would like to remind you of a few of the rules below and the reasons why they are so important:

- You should review finances at coordinating team meetings. This helps you manage your cashflow effectively
- Analyse transactions within Online Accounting monthly so we can provide VAT information to HMRC regularly. The risk of penalties or inquiry increases if reporting is incorrect
- Banking must be within our cash pooling scheme, no other bank accounts are permitted. The scheme safeguards funds and reduces administration for groups
- Year-end documentation must be finished by January 31 each year. This includes sending: Internal financial controls checklist, December receipts & payments report and agreed upon procedures report (if required)
- Legacy funds which are over £20,000 must be forwarded to MSNC to avoid funds being built up in your account
- As part of our Anti-Fraud Policy, any fraud should immediately be reported to the Finance team to ensure that it is investigated
- Group financial records must be retained and stored securely for seven years to meet HMRC requirements

If you want more information or have questions, please get in touch.

Contact: Finance support team financesupport@mssociety.org.uk



Sharing your stories, good news and top tips.

Walk, roll or stroll to stop MS this September

MS Walk is back for 2019 and it's going to be bigger and better than ever! This September you can get involved in MS Walk London, MS Walk Belfast and the brand new My MS Walk. However and wherever you take part, you can be part of something special and together, we will stop MS.

Every penny you raise from your MS Walks will go to the Stop MS Appeal which will fund vital MS research. See the cover story for more.

My MS Walk

Always wanted to take part in an MS Walk but not been able to make it to our walks in London or Belfast? Well now you can! With My MS Walk you can get involved wherever you are by organising your own walk. It doesn't matter how far you walk or how many people you walk with. Whether you walk with old friends, new friends or four-legged friends, every step you take will take us closer to stopping MS.

How to get involved:

- Pick a date in September and a route and walk, roll or stroll to stop MS
- Invite as many of your friends, family and colleagues as you like to your walk
- We'll support you every step of the way and send you everything you need to hold a fantastic MS Walk

Stuart's story

If you still need a bit of inspiration to start organising your MS Walk, here is Stuart Nixon MBE's amazing story. Stuart is an MS Society Ambassador, former Vice-Chair and is now our My MS Walk Champion. He organised his own walk in 2013.

"For the MS Society's 60th Anniversary in 2013 I planned something special. 'Stu Steps Up,' a 60km walk around London,was a walk with a difference – because I can't. With a specially designed walking frame and support from my wife Marie and 'Team Stu,' we walked from Buckingham Palace around London and back. nine days,



60km and £75,000 later we made it. Tears, laughter, Guinness and ice cream all featured in what was the most emotional time of my life.

When planning my walk the most important thing was getting buy-in from those who were going to walk with me. Advertise your walk early so people have plenty of time to sign up. Keep the 'pot bubbling' with regular updates on your progress, how much you plan to raise (be ambitious but realistic) and how they can be part of the fun. Finding the right course is crucial. It must be safe, pretty flat and enjoyable to walk on – you've got to enjoy doing it.

This is all about raising money to help stop MS. Make lists of people, organisations, associations and people you know. For me it was about using all the connections I had, overcoming any reluctance to ask for money and making it as easy for people to make a donation."

Let us know if you're interested in taking part in MS Walk 2019 in any way or have any questions.

Contact: MS Walk team mswalk@mssociety.org.uk 0300 500 8084



For England



Royal Parks MS Superstars wanted!



Join our MS Superstar team on the 13th of October and run the stunning 13.1 route through the capital's world famous landmarks on closed roads at the 2019 Royal Parks Half Marathon event. If you're not much of a runner, join our amazing volunteer cheer squad and cheer our MS Superstars across the finish line!

2019 London Marathon

On 28 April almost 300 MS Superstars took on all 26.2 miles of the world famous London Marathon to help stop MS.

Volunteers helped make sure our runners had a fantastic day by turning out to cheer on the team at our Bermondsey, Tower Hill, and Westminster cheer points. Volunteers also helped ensure our runners had a fantastic welcome to our post-race reception after they had crossed the finish line and received their medal.

Sponsorship is still coming in, but we are hoping to have raised almost £700,000 from this year's event.

A huge thank you to everyone who helped make the day such a success!

Contact: Your area fundraiser

Contact: Your area fundraiser

For Northern Ireland

New foot and ankle splint service

We are delighted to announce a new addition to our physiotherapy service. With the help of the Coleraine Group, we've recently received a range of ankle and foot splints which may be helpful to those living with MS.

This trial service is run by our Neuro-Physiotherapist Rachel Flinn. With the aim to help those living with MS have the opportunity to 'try before they buy'. Our resident physio Rachel will provide a consultation, advice on what best suits the needs of each individual, a trial fitting of splints as well as information on where best to purchase these items.

If you would like to use this opportunity to try one of our splints, please call us and ask to be placed onto the Physiotherapy waiting list for an ankle or foot splint. Due to the Neuro-Physiotherapist's availability, walk-ins cannot be accommodated.

Contact: Northern Ireland reception nireception@mssociety.org.uk 028 90 802 802

Working with Local Companies

Working with local companies is a great way to raise both funds and awareness.

If you or your group have contact with local companies why not approach them about becoming a charity partner or a Charity of the Year – or even supporting a local event.

Find out who your members and their families work for. Their employers may well be open to us approaching them as well. But do please speak to us before approaching any companies with a national profile as we may well already be in contact.

The fundraising team hope to be attending the forthcoming Volunteer Forums and will be more than happy to chat about corporate opportunities and anything fundraising you wish to discuss. We look forward to seeing many of you there.

Contact: Your local LNO

For Northern Ireland

New nurses for Northern Trust

After years of active campaigning by the MS community, we are delighted to be able to say the Northern Trust now has two dedicated MS Nurses. As well as being involved in promoting the need for this provision over many years, we were also represented in the recruitment process for these nurses by lain Crosbie. Iain is a member of the NI Council and was a key member of the interview panel.

We're currently engaging with the new nurses on potential future areas of collaborative work to include things like courses for people living with Progressive MS, information sessions for those newly diagnosed and 'Meet My MS Nurse' events.

The addition of MS Nurses to the Northern Trust area will also have an impact on those currently receiving treatment in Belfast. With drug treatment and MS nurses now available in both Antrim Area Hospital and Causeway there is the potential for people to receive services much closer to home. Those currently receiving treatment in Belfast should be contacted by their MS Nurse in due course as these services begin to roll out.

If you have any questions, let us know.

Contact: Northern Ireland reception nireception@mssociety.org.uk 028 90 802 802

Get Involved

We also have some fantastic events coming up in the near future that your group can promote as a means of raising funds, including:

- Our fantastic Lagan Zip Slide on Saturday May 18
- Big Leap skydive on Sunday June 2
- All-new Sunrise Slieve Donard Walk on Saturday August 10

We'd love to see members or friends of your group get involved. Give us a call for more information and materials to help you promote these events.

If you have and fundraising related questions please get in touch.

Contact: Eve Shearer, Community & Events Fundraiser eve.shearer@mssociety.org.uk

For Scotland



Cyclist gears up for 200 mile Fife Bike Ride for MS

On Saturday 11 May the 'Big MS Ride' will see participants tour the Fife countryside, starting from St Andrews, tracing out the letters MS to raise awareness and funds to help stop MS.

This is the third year event organiser Richard Sanderson has run the event. His sister was diagnosed with relapsing MS in 2009.

The avid cyclist said: "Ultimately, I just really enjoy cycling and it feels good to do something for a good cause that I have a real connection to."

Morna Simpkins, our Scotland director said: "We really appreciate everything Richard is doing to raise funds to help stop MS.

It's an amazing challenge and we wish him and all the other riders who take part the best of luck."

People can sponsor Richard and the Big MS Ride here: bit.ly/2TVu8S5 Or visit the Facebook page: facebook.com/bigmsride/

We know our groups and supporters come up with lots of creative ways to raise funds. So in each edition of Teamspirit we're sharing one great example from Scotland. If you've got something a bit different going on please send us your stories!

Contact: Scotland Press Office scotlandpressoffice@mssociety.org.uk 0131 335 4050

Group showcase: Dumbarton and District

This group have had a great few months raising funds and awareness to help stop MS.

The group were named winners of The Community Voluntary Team Champions Award by West Dunbartonshire Council.

They were also the chosen charity for the Loch Lomond and Trossachs National Park for 2018, which raised over £7,000 to support their work. They've had lots of other great activities going on as well, including:

- A raffle in the senior rates mess at HMS Faslane
- A coffee morning held at St Augustine's Church in Dumbarton
- A song for a scone coffee morning fundraiser

And their new counselling service has even been recognised with a motion in parliament – going to show what can be achieved by fundraising to support people living with MS.

For more information about their amazing work, check out their Facebook page: facebook.com/MSDumbarton

We love to hear about your success stories – please send us them for inclusion in one of our publications or online!

Contact: Scotland Press Office scotlandpressoffice@mssociety.org.uk 0131 335 4050

For Scotland



Improving disability benefits in Scotland – share your views

The Scottish Government has launched a consultation on the benefits being proposed as part of the devolution of Social Security powers to Scotland. Benefits being discussed in the consultation include Personal Independence Payment (PIP), Disability Living Allowance and Carers Allowance. The Scottish Government have called this 'disability assistance'.

We want you to have your say, so the new system makes sense for people living with MS.

By taking part, you'll make sure the consultation is informed by real life experiences of people with MS. The consultation closes on 28 May, so there's still time to share your views

To read about the proposed new approach visit the government's website here: gov.scot/publications/social-securityconsultation-disability-assistance-scotland/

You can answer questions on the proposed new approach here: consult.gov.scot/social-security/ improving-disability-assistance/consultation/

It's a lot to take in, but we believe questions 50-59 are the most relevant.

You can respond to the consultation yourself, or feed your views into our response. We'd love to hear from you, regarding as many or as few questions you would like to respond to.

Contact: Keith Robson, Policy, Public Affairs and Campaigns Manager (Scotland) **scotlandcampaigns@mssociety.org.uk**

Two great challenges to take part in

Could you, your friends or family take part in one, or both, of these two great challenges coming up soon? We'd love to welcome you to our **#MSSuperstar team**.

Ben Nevis Night Hike

Climb Ben Nevis overnight and experience the beauty of a sunrise over the Scottish Highlands, on 24 August.

Challenge yourself to reach new heights in our fantastic event. We'll be waiting for you with a celebratory breakfast when you're done!

"Reaching the summit was amazing, everyone was just so buzzing to be there. The bacon rolls and coffee when you reached the bottom were a definite highlight as well!" Millie, MS Superstar

Kiltwalk

Sign up to one of this year's Kiltwalks and every £1 you raise during this event will come straight back to us, allowing us to support people affected by MS in Scotland.

Not only this, but an amazing 40% will be put on top of your donation thanks to the Hunter Foundation.

There are a number of distances and start times on offer, so choose your city and your tartan!

- Aberdeen 2 June
- Dundee 18 August
- Edinburgh 15 September

For more information or to sign up please contact us.

Contact: Fundraising team msfundraising@mssociety.org.uk 0131 335 4050

Team<mark>spirit</mark>

For Wales



My MS My Rights My Choices

Our My MS My Rights My Choices project team provides one-to-one support to people living with and affected by MS in Wales to access benefits, grants, employment rights and social care services.

In addition, the team is working closely with MS specialists and nurses based in hospitals throughout Wales to arrange information days.

These information days: 'Newly Diagnosed' and 'Living Well with MS', provide opportunities for people affected by MS to come together and learn about the condition, treatments and ways to manage symptoms.

So far the project has reached over 1,500 people in Wales.

Groups across Wales have already given tremendous support to the My MS My Rights My Choices project. Please continue to do this by sharing information about the project in your newsletters and social media pages.

We hear every day from people living with and affected by MS in Wales who are in desperate need of the support of the project – anything you can do to help reach more people would be appreciated.

Contact: My MS My Rights My Choices team mymscymru@mssociety.org.uk

Inquiry on neurological services

As you may be aware, we have been campaigning to improve access to services and treatments for people living with MS and other neurological conditions in Wales.

Whilst some progress has been made and the Welsh Government is taking our concerns seriously, it is disappointing to say that change is not happening fast enough.

We know only too well how much the MS community is struggling to access treatments and services – it is not good enough!

We will be working alongside the Cross Party Group on Neurological Conditions who will be undertaking an inquiry on behalf of the Health & Social Care Committee.

This Committee is a group of Assembly Members who examine legislation and hold the Welsh Government to account.

Evidence will be gathered at 3 sessions which will be held across Wales.

Our community will be involved in the inquiry and we'll also be asking you to contact Assembly Members.

Contact: Fiona McDonald, Policy, Press and Campaigns Manager **fiona.mcdonald@mssociety.org.uk**

For Wales



Stop MS Appeal launch

The MS Society's vision is a world free from the effects of MS and we are doing our bit in Wales to help fund world-class research to help us get there.

As part of our Stop MS Appeal, we've set up a steering group made up of people living with and affected by MS to promote the Appeal and organise events.

We are holding a concert in St Asaph Cathedral on Saturday 6 July featuring our incredible aMaSing Gwynedd & Môn MS Choir.

aMaSing was set up in 2013 to give people living with MS and volunteers from Gwynedd and Ynys Môn a chance to meet each week to sing together.

They will be joined by other fantastic choirs including Ysgol Esgob Morgan, Coastal Voices, Bangor Community Choir, Threnodey Choir, Ladies Barber Shop and Shades of Harmony.

We are also planning a reception in Cardiff in November (tbc) and a host of other events throughout Wales to promote the Stop MS Appeal.

All of our groups can play a huge part in making the Stop MS Appeal a success – from helping to promote events to asking your members to promote the Stop MS appeal with local individuals or businesses.

Contact: Sian Dorward, Fundraising Manager for Wales sian.dorward@mssociety.org.uk

North and Mid Wales update

Groups in North and Mid Wales have been without a Local Networks /External Relations Officer for some time.

Lynne and the team would like to say a big thanks to all our group coordinators and other volunteers who have been working with her to keep things ticking over.

Our aim is to recruit a Local Networks Officer post for North & Mid Wales.

In addition, we're changing the External Relations Officer position to cover all-Wales.

With new staff in place along with our My MS My Rights My Choices project team, we'll be doing our utmost to improve the support and services we give to the MS community across North & Mid Wales.

Contact: Lynne Hughes, Country Director Wales lynne.hughes@mssociety.org.uk

Dates for your diary

- The BIG Leap Cymru, June 2, Swansea Airport
- Zip World Velocity 2, June 8, Zip World (Penrhyn Quarry) Bethesda
- Snowdonia Challenge, June 28-30, Snowdonia
- MS Choir concert St Asaph Cathedral, July 6, St Asaph, North Wales
- TrekFest, July 6, Brecon Beacons National Park
- Wales End to End 2019 (Cycling), August 15–18, Anglesey to Cardiff
- Admiral Swansea 10km, September 22, Swansea
- Cardiff Half Marathon, October 6, Cardiff

Contact: Sian Dorward, Fundraising Manager for Wales sian.dorward@mssociety.org.uk

Classifieds



Share chalets

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

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

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

To find out more please contact NI reception at nireception@mssociety.org.uk or on 028 90 802 802.

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



Teamspirit directory



Our offices

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

MS Society Cymru

Baltic House Mount Stuart Square Cardiff CF10 5FH 020 8438 0700

MS Society Northern Ireland

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

MS Society Scotland

National Office Ratho Park 88 Glasgow Road Ratho Station Newbridge EH28 8PP 0131 335 4050

Support groups

Asian MS

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

Mutual Support

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

Women Against MS

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

Find us online

mssociety.org.uk volunteers.mssociety.org.uk facebook.com/mssociety twitter.com/mssocietyuk

Get in touch

Supporter Care supportercare@mssociety.org.uk 0300 500 8084

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

Feedback on Teamspirit

teamspirit@mssociety.org.uk