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May 2018

# Teamspirit



# Kiss Goodbye to MS this May

fter an amazing first year, we're Kissing Goodbye to MS again in 2018!

Together, in 2017, we raised an incredible £50,000 for MS research, and this year we hope to raise even more. To take part, all you need to do is give up your guilty pleasure in May, or simply take a #KissGoodbyeToMS lipstick selfie and spread the word on social media.

Whether you're binning the booze, cutting the caffeine or chucking the chocolate, you'll be helping to fund pioneering MS research. By joining a global movement, we have a louder voice. Together, we are strong enough to stop MS.

Sign up at mssociety.org.uk/kissgoodbyetoms and blow us a kiss on social media using #KissGoodbyeToMS.



### 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!

# Spring campaign – celebrating progress in MS research

This MS Week saw the launch of our Spring campaign – we're Kissing Goodbye to MS to continue to raise vital funds for MS research – but we also want to celebrate the amazing research progress that's been made so far. We've supported multiple major breakthroughs across the UK and believe we could transform MS treatment in our lifetimes.

If you've already shared information about it – thank you! Take a look at our lovely research hub on the website at mssociety.org.uk/research We'd love you to take a look and share our 'meet the researcher' videos and other content on your group's social media channels.

It's also not long until World MS Day on Wednesday 30 May. We'll be discussing the progress that's been made in developing disease modifying therapies (DMTs), as well as new insight into how prescribers make decisions about which treatments to recommend.

We'll also be launching a new series of interactive videos featuring people living with MS talking about their experience of deciding which treatment might be right for them, and what issues were important to them in making that decision. We hope these videos will improve understanding of DMTs and support people to make the treatment decision that's right for them. Look out for these videos and updates on our website and social media channels.

Audience: All Action: Share

# Special edition of Teamspirit coming soon!

This May you'll be receiving not one, but two editions of Teamspirit! As many of you will know, the General Data Protection Regulation (GDPR) comes in to effect on 25 May. We'll be sending you a Teamspirit: Data and Technology Special in the run up to this date to provide you with further support and information.

We want to make sure that you feel well prepared and know how best to handle and process the data you hold. If you haven't yet done so, see our GDPR FAQs at volunteers.mssociety.org.uk/GDPR-FAQ

This special edition of Teamspirit is a resource for you to keep, and will cover a broad range of data and technology topics, beyond just GDPR compliance.

We hope this will be a useful reference for you, and an interesting read! It will also provide you with all the contact details and where to find further support should you need it. So you'll have lots of the information you need in one place. And of course, we'll continue to keep you updated with any changes, updates and processes throughout the year as well.

If you have any questions about the GDPR at this stage, please contact our Data Governance team.

Audience: All
Action: Note

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

Team**spirit** 

For group volunteers and national support group committee members



### Living with MS events

Do you sometimes feel that information about living with MS is constantly changing? Are you looking for more opportunities to meet other people with an understanding of MS? Our fantastic Living with MS events in Scotland, England and Wales are a great opportunity to get up to date information from staff and MS professionals, as well as meet other people affected by MS.

We want our information events to be valuable and useful for everyone. They feature motivational talks, up-to-date information about our cutting edge research programme and workshops on topics such as work and benefits, and diet and exercise. There's something for everyone – from those who are newly diagnosed, to those who've been living with MS for a number of years, as well as family and friends.

There's also interesting exhibitors and healthcare professionals to meet as well as interactive activities to keep the whole family entertained and informed throughout the day.

We also run awareness talks which are around 2-3 hours long and typically on topics such as research and benefits.

Visit mssociety.org.uk/information-days to view dates, locations and how to book.

Audience: All
Action: Share

Contact: Conference and Events team conferenceadmin@mssociety.org.uk

### **Stop MS Appeal**

As many of you know, Stop MS is our ambitious appeal to raise over £100 million by 2024 for MS research.

It's the most important fundraising campaign we've ever done. The money will dramatically accelerate progress in developing treatments to slow and stop the progression of MS. Our plans include a big, innovative trial to rapidly test multiple treatments, working with the best MS researchers in the world.

We've already been raising money for this appeal from individuals and trusts since 2015. We're now aiming to launch a much more 'public' phase of the Appeal in spring 2019, with a campaign that will be impossible to miss.

We want the whole MS community to get excited about Stop MS as a once in a generation opportunity. We'd love to get your input, ideas and inspiration to help us do that.

In particular, we want to develop new fundraising activities that will appeal to our local groups, and we want to hear your ideas about what will work to engage people in your area (building on what you already do well) and what you need from us to make it happen.

Staff involved in planning the Appeal are joining some Volunteer Forums to discuss this. We'd also welcome input from any groups who want to get involved or have ideas. Please contact your LNO – we'd love to hear from you.

Audience: All
Action: Share
Contact: Your LNO



# You have the expert knowledge and experience we need



We believe that people with MS should be at the heart of our service development. Our Expert by Experience Network is a community of people living with MS who share their experiences, knowledge and skills to help shape services.

To deliver the best possible MS Society services we need the support of people affected by MS. We need you to tell us about your experiences and help us design, develop and improve our services. By joining our new network you'll be part of an influential online community. Working together means we can target our work to focus on the things that are important to you.

It's easy to get involved! You'll always be able to choose how much or how little you want to do. We'll contact you about opportunities to participate and support you to contribute. Find out more and join our online network at signup.mssociety.org.uk/page/16849/subscribe/1

Audience: All Action: Share

Contact: Eleanor Ogilvie,
Engagement, Involvement and
Empowerment Manager
eleanor.ogilvie@mssociety.org.uk

#### Volunteers' Week 2018

Volunteers' Week is a fantastic opportunity to recognise volunteers and celebrate their achievements. Volunteers' Week is taking place from 1–7 June this year. Here are just a few ideas to help you celebrate:

- organise an event to celebrate volunteers in your local group
- keep an eye on our Facebook and Twitter feed during the week and share your inspiring stories of volunteers on social media
- nominate volunteers for a Shining Star award
- · send a thank you card
- a simple 'thank you' goes a long way

You can find out more about Volunteers' Week 2018 at volunteersweek.org/

Audience: All Action: Share

Contact: Volunteering team volunteering@mssociety.org.uk



### **Policy updates**

Our Disclosure policy for England & Wales has recently been updated as part of our regular cycle of updates. This policy is a key element of our commitment to keep people safe. Thank you to everyone who ensures that DBS checks and updates are completed. Group Coordinators will have received a letter outlining key changes for local group volunteers and service providers.

As mentioned in the last edition of Teamspirit, a group of volunteers are helping to create new guidance on key policies, and this includes our Disclosure policy. New and refreshed guidance will be available for people involved in DBS checks later this month.

Our Resolving Volunteer Issues and Concerns (RVIC) policy is also being reviewed currently. Again, once this has been updated, volunteers will be helping to improve our guidance and information relating to it.

You can find these and other policies on the volunteer website.

Audience: All
Action: Share

Contact: Volunteering team volunteering@mssociety.org.uk

# Lap belts reminder and guidance

We've had a few reported accident and incidents involving wheelchairs recently, so we want to make sure that you feel confident supporting people using lap belts. A lap belt can help maintain posture and will prevent the wearer from slipping or toppling from their chair. Lap belts should be worn whenever a wheelchair is in use.

To fit a separate or wheelchair supplied lap belt correctly:

- ensure a correct sitting position (i.e. fully back in the seat) and that the pelvis is as upright and symmetrical as possible
- position the lap belt so that the hip bones can be felt above the belt
- adjust the length of the lap belt so that there is just sufficient room for your hand to slide between the belt and the body of the person in the wheelchair

Further advice about using wheelchair lap belts can be found on the volunteer website at volunteers.mssociety.org.uk/resources/599

Audience: All Action: Share

Contact: Health and Safety team healthandsafety@mssociety.org.uk



# Join our online training sessions

In the volunteer survey last year you told us that as well as recruiting and keeping volunteers, you'd like help with fundraising and using our online tools.

We have lots of support in place and a great deal of experience between us so we're pleased to announce a series of online, interactive training sessions to bring us together. These one hour sessions are open to anyone who volunteers with a Coordinating team, or is thinking about joining one and will be facilitated by our Learning and Development team. By attending, you'll:

- · meet other Coordinating team members
- discuss what it's like for your group and hear about others' experiences
- find out about the resources and support available to you in your role

We hope the following sessions are of interest:

- 19 and 21 June Volunteers: How to find and keep 'em
- 23 and 24 August Fundraising:
   Have fun while raising more locally

To find out more and book your place, please visit the events pages of our volunteer website at volunteers.mssociety.org.uk/events

Audience: All Action: Share

Contact: Volunteering team volunteering@mssociety.org.uk

### **Investing in Volunteers**

As announced in November, we're currently working to achieve Investing in Volunteers, the UK quality standard for good practice in volunteering. This will help us ensure that all of our volunteers have the best possible experience with us and feel safe, supported and recognised for their contribution. It's being overseen by a steering group including volunteers from all of our national councils.

We've already been making changes to improve volunteering. These have included:

- additional support for Coordinating teams (see previous article)
- exit surveys to gather feedback on why volunteers leave their roles
- improving our guidance on key policies including DBS checks (see article on page 5)
- making sure volunteers can ask for references if they leave their role

As part of our assessment towards the end of the year, volunteers across the UK will be interviewed by our assessors. This is absolutely not a test of our volunteers! It's because it's the experiences of our volunteers which are most important. A cross-section of volunteers in a variety of roles will be contacted and asked to share their views with an assessor in the summer.

Audience: All Action: Share

Contact: Volunteering team volunteering@mssociety.org.uk



### Reviewing our online shop

We're reviewing our online shop to improve the overall customer experience for users.

If you have experience of using the current online shop system and would like to provide feedback on what improvements you'd like to see then please contact Supporter Care. We'll keep you updated as we progress with this project.

### **Updates to resources**

#### 'Advanced MS: a guide for carers'

For carers of people severely affected by MS, this covers financial and practical help, social care, respite, hospital stays, the medical team, palliative care and more. Written with input from carers, content was also shaped by the 2017 MS Society-funded Queen Margaret's University study into carers' needs.

Both this and last year's 'Supporting someone with MS' replace our previous carers' resources.

#### Symptoms videos

We now have five exercise videos for fatigue, memory and thinking problems, muscle spasms/stiffness, balance and walking problems and bladder issues. Find them at mssociety.org.uk/exercises-ms-symptoms

#### **Updated resources**

A new booklet 'My child has MS' has replaced 2013's 'Childhood MS'. Made with the cooperation of Great Ormond Street Hospital, it's illustrated with images of 10 year old Lily and her parents.

Our DMT booklet is being revised in the second half of May. It'll be available only as a pdf until a new print version is produced later this year. The interim digital booklet will also cover stem cell therapy and cladribine.

'Social care: getting support from your council (Scotland)' replaces Essential #8 'Getting the best from social work services in Scotland'. It joins social care booklets for Wales and England.
One for Northern Ireland is on its way.

Our 'Moving more with MS' booklet and exercise DVD have been combined, with the DVD housed inside the booklet. Find it in the online shop under 'Moving more with MS package'. You can still order booklet and DVD separately.

The 'Work and MS: an employee's guide' booklet has now been put into the new format and brand.

Essential #5 'Vision and MS' has been updated and put into the new format and brand, with a new title of 'MS and your eyes'.

Lastly, our booklets 'Claiming PIP' and 'Claiming ESA' have been updated, with reassessments now covered.

Publications above are available from the online shop. Please remove from circulation any copies of previous versions.

Audience: All Action: Share

Contact: For online shop feedback – Supporter Care supportercare@mssociety.org.uk 0300 500 8084

For information resources – shop@mssociety.org.uk

# TUUU Research

### **HSCT** in the media

As you may have seen, in March the stem cell therapy HSCT hit the headlines again.

An international study showed HSCT is effective for people with highly active relapsing MS.

The MIST trial reported that HSCT can stabilise relapsing MS and improve disability in people who were still experiencing relapses even though they were taking a disease modifying therapy (DMT).

The results have been hailed as "hugely encouraging" by researchers Professors Basil Sharrack and John Snowden, who led the UK arm of the trial in Sheffield.

#### How did the MIST trial work?

110 people, who'd had at least two relapses in the past year while on a DMT, were recruited to the trial. Half underwent HSCT while the other half took DMTs recommended by their neurologist.

During the first year, only one person in the HSCT group had a relapse, compared with 39 people having relapses while taking a DMT. Some also saw a reduction in disability.

#### What next?

The results of the MIST trial are exciting, but further work is needed to see how effective HSCT is compared with the most effective (and aggressive) DMTs, such as alemtuzumab. We're working with the research community to make this happen.

#### Want to find out more?

We have lots of information on HSCT on our website: mssociety.org.uk/hsct Our Helpline team are also available if you'd like further details.

Audience: All Action: Share

Contact: MS Helpline

helpline@mssociety.org.uk

0808 800 8000



### **Direct Marketing update**

#### Spring appeal

The Spring Appeal was sent out to 35,000 supporters at the end of April. They were asked to support long-term research projects, such as our work on improving MRI analysis, through regular gift so we have steady, ongoing income for the future and can plan ahead with confidence. The reminder will be arriving with supporters on 19 May which discusses other long-term projects to support.

#### Summer raffle

The Summer raffle will open at the beginning of June, with a top prize of £4,000! The closing date for postal entries is Friday 17 August, and you can enter online at raffleentry.org.uk/mssociety until Thursday 23 August 2018. We're aiming to raise over £100,000 from the Summer Raffle.

#### **MS Weekly Lottery**

Play our MS weekly lottery – it's a fun and exciting way to support the MS Society and help stop MS for good. For just £1 a week you'll be in with the chance of winning £10,000 or another great prize.

Visit mssociety.org.uk/lottery or call 01628 820 116 (Monday-Friday, 9am-5pm) to enter.

Audience: All Action: Share

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

# Partnership with National Garden Scheme (NGS)

We're delighted that NGS have extended our partnership as their guest charity for a third year and have made a further donation of £145,000 to help improve care and support for the MS community. This brings their total contribution over the last three years to a magnificent £375,000.

Your contributions have been key to the success of this partnership so far. Thank you to all of you who've visited your local garden or took part in Gardens and Health week last year.

The 2018 season is now well underway with lots of new gardens to visit. Please do find a garden near you at ngs.org.uk/find-a-garden

Gardens and Health week was successfully introduced last year and this year will have more flexibility for visits and even more gardens open. NGS' biggest weekend is their Festival Weekend on 2–3 June with 300 gardens open to visit. NGS are also running their photo competition again, with an amazing range of prizes in six categories up for grabs. Entries are open until 28 August 2018.

Please do help us share the good news through your group's events, newsletters and social media to encourage supporters to visit gardens. NGS have a super app and lots of information on the website about the gardens, their facilities and accessibility.

To get involved or find out more go to ngs.org.uk

Audience: All
Action: Share

Contact: Your Area Fundraiser



# Sainsbury's bucket collections reminder

Last year we updated you about changes to Sainsbury's bucket collection procedures. Sainsbury's charity bucket collections are now counted and banked by the store. The collections are then paid over to the MS Society via Charities Aid Foundation (CAF).

Although Sainsbury's ask for the group's bank details, the funds are transferred to MS National Centre, as CAF aren't able to hold more than one beneficiary account for the same charity number.

This money is then transferred to groups on a monthly basis. If you're aware of any outstanding money from a collection intended for your group, please contact your Area Fundraiser.

Audience: All Action: Share

Contact: Your Area Fundraiser



# Update on contactless donation boxes

In a recent edition of Teamspirit we let you know that we were looking in to contactless donation boxes for use when bucket collecting. Thank you to those who've registered your interest in these for your group. There's still time to register your interest – please get in touch with the Finance team on the details below.

We're currently looking at a number of different providers to find the best option for groups. To give an idea of cost, one of the best quotes we've had so far is £150 for a contactless collection box and then a 2.65% transaction charge but with no set up costs. Some providers also allow you to rent collection boxes but pricing seems quite expensive. We'll continue to approach other providers and will keep you updated.

Audience: All

Action: Note, act – register your interest

Contact: Finance team

financesupport@mssociety.org.uk

## **Online Accounting upgrade**

Thank you for your patience while Online Accounting was recently upgraded. We're really excited to let you know about some of the new features which are now available to you.

- Account Notes You may have noticed a new 'Account Notes' section in the Bank Account area. This is optional for your group to use and allows you to make useful notes, such as listing any outstanding cheques or lodgements you wish to monitor.
- Reports When you next run your group's
  Receipts and Payments Report you'll notice
  new budget columns. Last month, we emailed
  (to your group's email address) an optional
  budget template for your group to complete.
  Once returned to the Finance team, we'll
  upload these figures into your account
  which will then be displayed in your monthly
  reporting. We hope this will help you to
  monitor budgeted spend against actual.
- Noticed a mistake? No problem, please send an email to finance.support@mssociety.org.uk or give us a call on 0131 335 4078 / 0208 438 0875 and we can easily correct any mispostings. Once we've done this the adjustment will be reflected in your reports after 24 hours.

If you'd like to discuss any of the new features or have any questions please do get in touch.

Audience: Finance Volunteers

Action: Note

Contact: Finance team

financesupport@mssociety.org.uk



# For Northern Ireland

#### **IT Matters**

Our Big Lottery 'Awards for All' funded programme, IT Matters, is now underway, to help improve IT skills for our volunteers and groups.

IT Matters is a six week programme and is currently taking place in Belfast and Omagh. The sessions cover social media, email, keeping safe online, Web to Print, the Portal and online volunteer recruitment. It's an excellent opportunity to improve skills and become an IT champion for your group.

We're currently planning another set of IT Matters sessions for autumn. One will be running in Ballymena and another in Craigavon. If you'd like to take part please get in touch and we can sign you up for this exciting new programme.

Audience: Northern Ireland

**Action:** Share

Contact: Your LNO or NI reception nireception@mssociety.org.uk

#### **MS Cafés**

The Belfast group is working on different ways to reach people affected by MS, in new locations. They've been working with their LNO to develop ideas and will be using MS Cafés.

MS Cafés will be informal drop-ins held in local cafés, garden centres... anywhere people living with MS can come together for a chat, support, and to make friends. The MS Cafés are for anyone affected by MS and aim to offer support, as well as ensure people are aware of other local and national MS Society support and services available.

We hope to have some Cafes organised throughout Belfast in the next few months.

These cafés will all be hosted by volunteers – if you'd like to get involved, host an MS Café, or have an idea for a venue please do get in touch.

Audience: Northern Ireland

Action: Share

Contact: Paula McLarnon, LNO (Northern Ireland – North)

paula.mclarnon@mssociety.org.uk



# For Northern Ireland

### Run for Research is back!

We're delighted to announce that Run for Research is back for 2018 and will be taking place on 7 October at Holywood Exchange.

Our first Run for Research, in April last year, was a huge success with 10km and half marathon distances. We had almost 600 runners taking part. All the local running groups got involved, and lots of support groups for young people with MS came along. We had an MS Society stand at the start, and it was great seeing people finding out about the support that's available.

This year, the event is going to be even bigger! As well as the 10k and half marathon, we'll be offering a 20 mile distance for those working towards the Dublin Marathon and we're also looking to add a family fun run.

This flagship running event is led by volunteers, including NI Council members, Ivan Prue and Jennifer Coulter. It's a big event and we need lots of help. If you can volunteer to help organise or want to get involved please contact the Fundraising team.

#### Research talks

Also on the theme of MS research, we're holding two research events this month:

- 11 May, 2:30pm-6pm –
   Everglades Hotel, Derry
- 12 May, 10:30am-2:30pm Crowne Plaza, Belfast

Audience: Northern Ireland

Action: Share

Contact: Tom Mallon,

Fundraising Manager Northern Ireland

tom.mallon@mssociety.org.uk

### Raising funds for your group

We have a number of fundraising events coming up and we'd love you to get involved!

If you'd like to Kiss Goodbye to MS or organise a Cake Break, give our Fundraising team a call. We also have a series of activity based fundraisers that you and your group can get involved in including:

- Over the Top Abseil –
   Belfast Castle on Sunday 24 June
- Tough Mudder –
   Co. Meath on Saturday 21 and Sunday 22 July
- Slieve Donard by Moonlight Newcastle, Co. Down, on Saturday 11 and Sunday 12 August

#### Stop MS Ball - save the date

Our fantastic 'Stop MS' Ball will take place at the Stormont hotel, Belfast on Saturday 17 November. The Ball is our showcase event for 2018 and we'd love to see your group there. The 'Black Tie' event will kick off with a drinks reception, followed by a four course dinner, after dinner speaker and then dancing to the HouseM8s – who are returning by popular demand. Tickets are £50 and you can register your interest by emailing nireception@mssociety.org.uk



Audience: Northern Ireland

Action: Share

Contact: Tom Mallon,
Fundraising Manager Northern Ireland
tom.mallon@mssociety.org.uk
02890 802 802





# For Scotland

# Could you be an Insight Volunteer?

We're looking for more Insight Volunteers in Scotland to make sure our publications are relevant to people living here. This is particularly important now, with big changes in Scotland such as health and social care integration and a new social security (benefits) system.

This is a great role if you'd like to volunteer from home. All you need is personal experience of living with MS, and an interest in our publications and the information we provide.

Whether you have MS or are a friend or family member of someone living with MS, we'd love to hear from you!

To find out more please visit: mssociety.org.uk/insight-volunteer-reviewingour-information-resources

Audience: Scotland

Action: Share

Contact: Richard Scholey,
Information Resources Editor
richard.scholey@mssociety.org.uk

# Scottish Government to pay supplement to Carer's Allowance

Carer's Allowance can be paid if you care for someone for more than 35 hours a week and they receive certain benefits.

Currently delivered by the UK Government, it's one of a range of benefits being devolved to Scotland.

The Scottish Government is committed to increasing the amount paid to carers. Initially, they will pay this as a supplement, which will increase the level of Carer's Allowance to that of Jobseeker's Allowance. The supplement will be paid twice a year rather than weekly. Payments of Carer's Allowance Supplement will begin in Summer 2018 and planned to be backdated to April 2018.

Eventually, a Scottish social security agency will be established and the Scottish Government will pay all of Carer's Allowance with the increase. Before that, the Department for Work and Pensions (DWP) will continue to pay the main Carer's Allowance and the Scottish Government will pay the supplement.

If you're already receiving Carer's Allowance, you won't need to do anything – you will automatically receive the supplement. If you're not receiving Carer's Allowance and you are a carer, find out about eligibility at <a href="gov.uk/carers-allowance">gov.uk/carers-allowance</a>

You can read more about the Scottish Government's plans for Carers Allowance at beta.gov. scot/policies/social-security/benefits-for-carers/

For more information please contact our MS Helpline.

Audience: Scotland

Action: Share

Contact: MS Helpline

helpline@mssociety.org.uk

0808 800 8000





# For Scotland

# Cheering at the Edinburgh Marathon Festival



At last year's Edinburgh Marathon Festival Gillian, her daughter Sophie and her friends joined our Cheer Squad to cheer on our #MSSuperstar runners. Gillian said: "We loved being part of the #MSSuperstars cheer squad team. It was so much fun cheering on all the runners to the finish line. We can't wait to come back in 2018!"

Could you help cheer our #MSSuperstar runners on at this year's Edinburgh Marathon? We'd love you to join our Cheer Squad on Sunday 27 May. The weekend is shaping up to be amazing with 120 runners already signed up!

If you can spare an hour or two, please join us and cheer on all of the #MSSuperstar runners in the team relay, half and full marathon.

As part of the Cheer Squad team you'll receive one of our orange-tastic t-shirts and lots of flags and cheer sticks to give the runners that extra boost to the finish line – plus lunch and snacks to keep your energy levels up.

For more information and to sign up please get in touch on the details below.

Audience: Scotland

Action: Share

Contact: Scotland Fundraising team msfundraising@mssociety.org.uk

0131 335 4063

# Living Well with MS sessions 2018

We've now booked all our Living Well with MS sessions for the year. Please help us spread the word in your area.

The sessions are aimed at people newly diagnosed with MS following feedback from our pilot last year. They're held over two half days and give people the chance to get to know others who've recently been diagnosed. Following the sessions people are offered the opportunity to stay in touch with others online.

Read more about the sessions at mssociety.org.uk/living-well-ms-sessions

- 17 and 31 May Glenrothes, Fife
- 13 and 27 June East Kilbride, South Lanarkshire
- 28 August and 11 September Edinburgh
- 4 and 18 September Kilwinning, North Ayrshire
- 8 and 22 September Glasgow
- 11 and 25 October Shotts, North Lanarkshire
- 10 and 24 November Alloa, Clackmannanshire
- 12 and 26 November Paisley, Renfrewshire

Audience: Scotland

Action: Share

Contact: Susi Paden, Self Management Programme Coordinator, or Coleen Kelly, Self Management Lead receptionratho@mssociety.org.uk 0131 335 4050





# Fundraising groups in Wales

Following last year's successful pilot of Fundraising groups we now have two groups established, in Cardiff and Swansea.

Upcoming planned events include a Black and Orange Ball, a dinner, a Wheel and Walk from Swansea to Mumbles, and a skydive.

If anyone is interested in lending their skills and time to help raise vital funds for MS Society Cymru by joining the existing Fundraising groups, or establishing their own group, we'd love to hear from you.

Our new Fundraising Manager for Wales, Sian Dorward, will be attending groups and Volunteer Forums over the coming months to talk about community grant opportunities and to support groups in making applications.

If you have any queries about fundraising events and local funding opportunities, please contact Sian to discuss.

Audience: Wales
Action: Share

Contact: Sian Doward,
Fundraising Manager Wales
sian.dorward@mssociety.org.uk
07802 721513

### **Treat me Right update**

Access to MS treatments and services is still the number one priority for people living with MS in Wales.

We've produced a report and sent it to the Cabinet Secretary for Health in Wales to outline our concerns. MS Specialists have expressed their worries over the lack of capacity and the impact this is having on access to treatments and services.

We're also active at a local level:

#### **Aneurin Bevan (Gwent)**

A roundtable event is planned for later this year with people living with MS, Assembly Members and hospital managers to focus on improving services for people with MS in the area.

#### Abertawe Bro Morgannwg (Swansea)

People living with MS who receive monthly Tysabri infusions at Morriston Hospital have been creating digital case studies to highlight the impact of frequent disruptions to the service. Their experiences will be used to gain the support of ABMU Health board and local Assembly Ministers to improve access to the infusion clinic.

#### **Betsi Cadwaladr (North Wales)**

People living with MS have formed a campaign group to highlight the difficulties accessing services in North Wales. A roundtable event is planned for later this year with people living with MS, Assembly Members and hospital managers.

Audience: Wales
Action: Share

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



# My MS, My Rights, My Choices – key dates

We have lots of upcoming events to provide support and information, as well as opportunities to meet others living with MS. Please see below dates for 2018.

#### Information days:

- 15 May Flintshire (Information Café)
- 30 May- Llandudno (Digesting Science)
- 31 May Wrexham (Digesting Science)
- 5 June Wrexham (benefits and grants)

#### Progressive MS research conferences:

Last year's highly successful conference organised by the Conwy & Denbighshire group taught us that there's a real need for people living with progressive MS to have more information about ongoing developments for their specific condition. With this in mind, the My MS, My Rights, My Choices project team will be organising two further conferences on Progressive MS;

- 5 October Bangor Ty Menai Parc Menai
- 6 October Carmarthen

Audience: Wales
Action: Share

Contact: My MS, My Rights,

My Choices team

mymscymru@mssociety.org.uk



# **Group contributions**

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

Group contributions 02/02/18 to 23/03/18				
Group Name	Earmarked Description	Earmarked	Research	General
Blackpool Fylde & Wyre group	Cambridge Myelin Repair Centre	£200,000.00		
Braintree group			£500.00	
Coleraine & District group				£1,500.00
Dereham & District group	Cambridge Myelin Repair Centre	£2,500.00		
Dereham & District group			£2,500.00	
Doncaster & District group			£130.00	
East Berkshire group	Research Uni of Portsmouth/ Uni of Glasgow	£5,000.00		
Hillingdon group	Cambridge Myelin Repair Centre	£5,000.00		
Hillingdon group	Stem Cell Research	£5,000.00		
Llandrindod Wells & District group	Stem Cell Research	£2,000.00		
Merton group			£2,000.00	
Newmarket & District group	Cambridge Myelin Repair Centre	£20,000.00		
Northamptonshire group			£10,000.00	
The Multiple Sclerosis Society of Jersey			£700.00	
West Hertfordshire group	Cambridge Myelin Repair Centre	£2,000.00		
Total		£241, 500.00	£15,830.00	£1,500.00



# Holiday lodge and bungalow

The Bexley & Dartford group have a holiday lodge for people with MS and their families at Shorefield Holiday Village, Milford on Sea, near Lymington, Hampshire. The lodge is fully adapted for disabled people and wheelchair users, and has a master bedroom with en-suite shower room and hoist, a twin room, bathroom, and lounge/kitchen area with sofa bed.

The group also have a detached two bedroom bungalow at Eastbourne, Sussex, on a peaceful private estate close to Sovereign Harbour.

Fully equipped (no fixed hoist) for people with MS and their families and furnished for 4/6 people.

For enquiries or bookings for 2018 for both properties, please contact the Bexley & Dartford group on 0208 306 7050 or email bexley@mssociety.org.uk.

### **Holiday lodge**

The North Norfolk group run a Holiday Lodge at Burgh Castle, near Great Yarmouth, Norfolk, for people with MS, families and carers. The lodge sleeps six with a bed-settee in the lounge, a twin room with en-suite shower and a double room with overhead hoist running into wet room.

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

#### **Share chalets**

The team in Northern Ireland have two fully accessible chalets for hire at the Share village n 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**

Temple Court Cathedral Road Cardiff CF11 9HA 020 8438 0700

#### MS Society Northern Ireland

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

#### **MS Society Scotland**

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

# Feedback on Teamspirit

teamspirit@mssociety.org.uk

### **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