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May 2017

# Teamspirit



Our Mid Ulster group 'MS Society Group of the Year 2017' with our celebrity supporter Alun Armstrong

# MS Society Awards 2017

The MS Society Awards 2017 took place on 5 May in London. It was a fantastic day celebrating all the incredible work carried out by the MS community right across the UK. Awards were presented in 16 categories including MS Society Group of the Year and Volunteer of the Year. We're pleased to announce that the Mid Ulster group from Northern Ireland (pictured above) scooped the Group of the Year award and Tom Hunter, also from Northern Ireland, was awarded Volunteer of the Year. To find out more about the event and to see the full list of winners and finalists please visit mssociety.org.uk/awards

Team**spirit** 

For group volunteers and national support group committee members

## 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!

# **Achievements reports**

Looking back on 2016, we're inspired by all that our passionate, committed MS community has achieved. We're stronger when we share our experiences, support each other, and work together for change. At the end of April, we published our Achievements Report for 2016, which looks back on some of the highlights of last year. You can see the Achievements Report at mssociety.org.uk/ms-resources/strongertogether-stop-ms-our-achievements-2016 and share it with your group.

Our number one goal for 2015-2019 is to ensure everyone with MS has access to effective treatments. Our Treat Me Right campaign continued to fight for access to treatments for people with MS. Thanks in part to the campaign, more people than ever before are using a DMT for their relapsing MS. In 2016 56% of people who could benefit from a DMT were taking one, this is up from 40% in 2013.

One of our biggest achievements of 2016 was through our MS: Enough campaign, which calls for a welfare system that supports people with MS to live independent lives. In March 2016, we led a group of charities in successfully campaigning to stop some of the Government's proposed changes to Personal Independence Payment (PIP), which could have seen people with MS lose out on up to £150 a week. We couldn't have achieved this without our community – almost 23,000 of you signed our petition, and more than 3,000 of you emailed your MPs. In 2016 we continued to provide support and information for people living with MS – our MS Helpline handled 17,437 enquiries, our national grants programme helped over 1,600 people access more than £780,000 in grants, our information resources were downloaded over 68,000 times and we sent over 93,000 copies to people who requested them.

On a local level, our groups provided friendship, information and support for around 13,000 people living with MS. More than 5,000 of you volunteered over 700,000 hours of your time to support our work. Without you, none of this would be possible – thank you for all that you do.

We achieved so much together in 2016. But we also understand that people affected by MS faced many challenges, and that there are more that lie ahead. With your help, we'll continue to fund life-changing research, campaign for a fairer health and social care system, and provide friendship and support when it's needed most.

Audience: AllAction: Share

**News and events** 

# Activity in our local networks

We're in the process of reviewing our approach to day centres, holiday homes and shops that are managed by local groups. We're looking at how we manage these activities and provide support to local volunteers who run them. This review involves 22 groups from our network of approximately 260 groups.

It's important that all activities are safe, and make the best possible use of our charitable resources. We want to ensure people with MS receive high quality services, which meet their needs and make a positive difference to their lives.

An external firm will be helping with this review, providing an independent and objective assessment of how well our current approach is working.

We contacted the groups involved in this review earlier in the year and this month the independent auditor is speaking to and visiting them. We'll then consider any recommendations made and will be talking to local groups about the recommendations in the autumn.

- Audience: All
- Action: Note
- Contact: Local Networks Programme team localnetworkprogramme @mssociety.org.uk

## Help us make improvements to welfare and employment

We'll soon be recruiting to our advisory panels to inform our positions on public policy. This is an exciting opportunity to help us fight for improvements in welfare and employment for people affected by MS.

David, one of our current panel volunteers, said:

"Membership of the MS Society's Welfare and Employment Panel provides a real opportunity for people with MS or those who care for them to use their practical experience in helping to develop the MS Society's policies on welfare and employment issues. I would encourage anyone with an interest in contributing to this important element of the work of the MS Society to consider putting their names forward and joining my colleagues and me on this panel."

The role of these volunteers is to ensure that our approach to policy development results in effective, evidence-based positions that reflect the views and concerns of people with MS. This includes activities such as reviewing our position statements, and our responses to Government consultations. It's predominantly a home-based role, using email.

Please share with your group members or anyone who may be interested in the role. Details about this volunteering opportunity will shortly be available at mssociety.org.uk/ volunteering-opportunities

- Audience: All
- **Action:** Share
- Contact: Laura Wetherly, Policy Manager – Welfare and Employment laura.wetherly@mssociety.org.uk 020 8827 0210

**News and events** 

## Volunteers' Week

Volunteers' Week 2017 takes place 1–7 June, and is a national celebration of the incredible contribution volunteers make in local communities.

And our volunteers are no exception. You are at the heart of what we do; providing support and services to local people affected by MS, making a real difference every day.

This Volunteers' Week we'll be saying a big thank you to all of you who do so much to support others in so many ways. Keep an eye on our social media channels for videos, messages and inspirational volunteer stories – please do share, like and retweet!

Volunteers' Week is also a fantastic opportunity for local groups to recognise and thank your volunteers. You may like to:

- Host a Volunteers' Week event to celebrate the contribution of volunteers or thank someone in particular. You could use Web to Print to create flyers to advertise the event.
- Give gifts of chocolates or a flower bouquet. You could approach a local business to donate these.
- Send handwritten notes of appreciation.
  You can request 'thank you' cards from the Central Admin team (contact details below).

The NCVO (National Council for Voluntary Organisations) have created a resource pack with everything you need to help plan your celebrations, visit http://tinyurl.com/mqqto88

- Audience: All
- Action: Share
- Contact: Volunteering team volunteering@mssociety.org.uk Central Admin team ssadminhelpdesk@mssociety.org.uk 020 3828 6861

#### Get involved in Carers Week

Carers Week is coming up on 12-18 June. This is a week dedicated to celebrating friends and family who make living with MS easier.

We want to make sure that our carers feel appreciated. We also want to raise awareness about caring to highlight the challenges carers face and ensure they have the support they need.

Carers Week is happening all over the UK. You can get involved by:

- Sharing our new carers' booklet coming out in June. It will be available in our Online Shop.
- Organising a coffee morning, award ceremony or other event that celebrates carers with your local group.
- Recognising a carer-friendly local service on the Carers Week website at carersweek.org

You can also find posters, flyers and materials to help you host an event on the Carers Week website.

- Audience: All
- Action: Share
- Contact: Campaigns team campaigns@mssociety.org.uk

1) Info and resources

#### **New resources**

#### Benefits and MS

With content provided by Disability Rights UK, this booklet covers the whole of the UK and looks at a wide range of benefits. Please note, it doesn't replace our popular PIP and ESA booklets, which are still available.

#### **Updated resources**

We've recently given a make-over to two of our publications and revised their content.

- Social care: getting support from your council (England version)

This booklet replaces *Getting the best from social care services (England version).* A booklet on social care for Wales will be available in the next six weeks, and we hope to soon be able to provide the same for Scotland and Northern Ireland. Until these are available, much of the content of the England version will be useful to those in other nations also.

Moving more with MS

This replaces *Essential 21 Exercise and physiotherapy*. It looks at the benefits of being active, and support available to help stay active.

These booklets are now available from the online shop. Please remove from circulation any copies of the two replaced resources – *Getting the best from social care services (England version)* and *Essential 21 Exercise and physiotherapy.* 

#### **Revised Factsheets**

Three of our existing factsheets have now been updated:

- Posture and movement 1
- Posture and movement 2
- Bereavement

#### We've been listening!

We've been looking at how well we provide information about MS and living with MS. We've carried out focus groups in Scotland and Northern Ireland, plus had feedback by email and over the phone from around 50 professionals and people affected by MS. We've gained a lot of insight into what people think of our new look publications. The good news is – they got a thumbs up!

However, we also heard what information gaps needed to be filled and this will help us decide what new resources we need to add to our range. We'll be using all the information gathered to guide us as we update our current information resources, making our information resources even better for people affected by MS.

- Audience: All
- Action: Share
- Contact: Information Resources team shop@mssociety.org.uk
   020 8438 0999

# **IIII** Research

# Simvastatin phase 3 trial announced

We're proud to announce that we're co-funding a phase 3 trial to test if simvastatin could become a treatment for secondary progressive MS.

The phase 3 trial will involve over 1,000 people with secondary progressive MS. The trial started setting up in March and will take six years in total to complete.

If successful, simvastatin could be the first treatment licensed for secondary progressive MS.

The phase 2 trial results for simvastatin were published in 2014. Researchers found that people taking high doses of simvastatin had better disability scores compared with those taking placebo. Simvastatin also reduced the rate of brain atrophy (shrinkage) over two years.

Following these successful results, work began on the phase 3 trial. Research Manager Marie Braisher said: *"We started thinking about this trial almost immediately after the phase 2 trial finished in 2014. There was a huge desire to move forward…it's brilliant to see it becoming a reality."* 

We're funding this £6 million research in collaboration with the National Institute for Health Research, the National MS Society (US), the NHS and UK universities.

To learn more about the trial, please visit mssociety.org.uk/ms-stat2

- Audience: All
- Action: Share
- Contact: Helpline helpline@mssociety.org.uk 0808 800 8000

# Let's talk about HSCT

With every new research paper we learn more about HSCT (haematopoietic stem cell transplantation) and who's likely to benefit.

We know many people are wondering if it's for them, and so we've updated our website to help answer these questions. This includes explaining what HSCT is, who it works best for, what you can expect, and ways of accessing the treatment. See mssociety.org.uk/hsct to read more.

Research shows this therapy holds the most promise for people who are having frequent relapses. For them, it can stop these relapses and even stabilise or improve disability. But for others, HSCT does not seem to bring the same level of benefits.

HSCT is also not without risk. It's an intensive treatment involving chemotherapy and to date, around 1% of people who've received HSCT have died.

If you're considering HSCT please speak to your neurologist. They're the only person who can refer you for treatment on the NHS. They should also be able to talk to you about your treatment options and what's best for you.

You can also watch our recent webinar with neurologist and HSCT specialist Professor Basil Sharrack, and Mark Rye who recently had HSCT on the NHS, answering viewers' questions. Visit: crowdcast.io/e/lets-talk-about-hsct to watch.

- Audience: All
- Action: Share
- Contact: Helpline helpline@mssociety.org.uk 0808 800 8000

# 'IT' Fundraising

## The National Garden Scheme

The National Garden Scheme's (NGS) festival weekend is on 27-29 May! NGS are celebrating their 90th Anniversary, opening around 380 beautiful gardens for a weekend of celebration and horticultural delight.

By opening up gardens and raising money through entry fees, teas and cake the NGS have donated an incredible £50 million to nursing charities so far. We're delighted to share the news that this year they've donated a generous £130,000 to the MS Society. This is an increase from the £100,000 donation we received in 2016.

These beautiful private gardens can be visited by family, friends and enthusiasts alike. So don't miss out on visiting one of the many wonderful festival gardens and help raise funds for us and other amazing causes. With special events such as craft fairs, exhibitions, cake and more – you're guaranteed to have a *blooming* good day!

Find a garden near you by visiting **ngs.org.uk** and use the Garden Finder to search for gardens by location, date and accessibility. A smartphone app is also available.

- Audience: All
- Action: Share
- Contact: Charlie Bartlett, Community and Events Officer charlie.bartlett@mssociety.org.uk

# **Direct Marketing update**

#### Raffle

Thank you to everyone who entered or donated to the Spring Raffle. Thanks to the amazing response, at the time of going to press, we'd raised £118,000. The winners were drawn on 5 May.

The next raffle will be sent out to supporters, donors and members in early June. We hope you'll all be keen to take part again.

#### **Progressive MS appeal**

Our appeal which is raising money for progressive MS projects and which focussed on the work of the International Progressive MS Alliance, landed with many of your members last month. This Alliance is a network of MS charities from around the world united to achieve one key goal: to speed up the development of treatments for progressive MS. I hope your members found the appeal interesting and are excited by the developments this area of research is making.

#### Summer advances

The next edition of our supporter magazine, *advances*, lands in July. We raised a fantastic £62,000 from the January edition – thank you so much for all your support!

If any of your members don't receive *advances* anymore and would like to be added to the mailing list, please ask them to get in touch.

- Audience: All
- Action: Share
- Contact: Supporter Care supportercare@mssociety.org.uk 0300 500 8084

# Medium and psychic fundraising events

We're aware that a few groups and volunteers have recently held fundraising events featuring mediums and psychics. While it's always great to see groups finding new and interesting ways to raise funds, these kinds of events are controversial and can raise concerns among the public and our own volunteers.

While for some this kind of activity is fun and of interest, they can cause offence and objections. As a secular organisation we respect all our members' beliefs, but do not endorse one set over another. Therefore, our policy is not to organise or promote these kinds of events, including group organised events. This has been the organisation's position for a long time and has not changed.

We understand for some this will be disappointing, particularly for those who may have been unaware and in the process of planning an event, but there's a huge range of other activities and events that we can give guidance on. For more information on fundraising ideas please do get in touch with your Area Fundraiser - you can find their details at volunteers.mssociety.org.uk/area-fundraisers

- Audience: All
- Action: Note
- Contact: Your Area Fundraiser

# Changes to Sainsbury's store collection procedures

Some of you may be aware that Sainsbury's have recently amended their procedures for charity collections. The main changes are:

- sealed tins will be collected by Sainsbury's staff at the end of the day
- money will be counted by Sainsbury's staff in their secure cash room and then banked by Sainsbury's and transferred directly to the group bank account

We're currently discussing with Sainsbury's whether our volunteers can be involved in the counting and agreeing the final amount collected prior to banking. Sainsbury's are firm about banking the money and transferring directly, to reduce an increase in fraudulent collections they've experienced with charity collections. They're open to improving parts of the process to make it as easy and transparent as possible for charities.

While we're in discussion, we ask all groups to continue with their usual collections and follow the guidance laid out by Sainsbury's. While some groups have had relationships with local stores for many years, Sainsbury's offer us a great opportunity by inviting us to collect in-store and therefore we need to respect their decision to amend their procedures.

More detail on Sainsbury's procedures can be found on the volunteer website at volunteers. mssociety.org.uk/street-store-collections

If you have any questions or concerns, please contact Mark Haymes.

- Audience: All
- Action: Share
- Contact: Mark Haymes,
  - Area Fundraising Manager (England) mark.haymes@mssociety.org.uk 020 8827 0336



# Banking

Barclays have informed us that the time we should allow for bank mandates to be processed is now 20 days rather than 10 days.

Please bear this in mind when submitting your new bank mandate. If you have any queries or require further assistance, please contact Treasury Support.

- Audience: All
- Action: Note
- Contact: Treasury Support treasurysupport@mssociety.org.uk

#### **Group finances**

It's important that group coordinating teams share the responsibility of maintaining group finances, supporting the Finance Volunteer. Here are our top tips on managing group finances for the whole team:

- Assess the financial controls in operation and how these can be maintained or improved – a key document to assist you to do this is the Internal Financial Controls Checklist (IFCC) and this should be reviewed on an annual basis.
- Plan and budget together as a coordinating team, outlining what you want to achieve and then working out expected cost and whether you can raise funds to cover the costs.
- Discuss finances at your group meetings and review income and expenditure. The financial reports should reflect the activities you've undertaken – if they don't, it could indicate that there is something wrong in the group's finances.

Accounting Online provides reports which can assist you with this, including:

- Receipts and Payments report provides a breakdown of each income and expenditure code for a specified period.
- Transaction report provides a detailed breakdown of each income and expenditure code.
- Events/Funds Receipts and Payments report – provides similar analysis to the main Receipts & Payments report but allows reporting on a specific event or restricted fund for a specified period.
  - Audience: All
  - Action: Note
  - Contact: Finance team financesupport@mssociety.org.uk 0131 335 4078 / 020 8438 0844



## **VAT updates**

HM Revenue & Customs (HMRC) have recently changed the rules on claiming VAT relief on adapted motor vehicles for wheelchair users. The following changes will take effect from 1 April 2017:

- Individuals will only be able to purchase one vehicle that qualifies for VAT relief every three years. HMRC refer to this as the '3-year rule'. There are a few exceptions to this rule, please see below for further details
- The individual must provide an 'eligibility declaration form' to the supplier upon purchasing a vehicle that qualifies for VAT relief
- HMRC will issue a penalty to any person that provides an incorrect 'eligibility declaration form'

Exceptions to the 3-year rule apply if you're purchasing a qualifying vehicle under the following circumstances:

- the vehicle was stolen, destroyed or damaged beyond repair in circumstances beyond the control of the individual
- the wheelchair user's condition changes and because of this the vehicle is no longer suitable for use by that person

For further guidance please see section 9 of the Treasurers Handbook, available on our volunteer website.

Alternatively if you have any queries, please contact the Finance team.

- Audience: All, especially Finance Volunteers and Lead Coordinators
- Action: Share
- Contact: Finance team
  financesupport@mssociety.org.uk
  0131 335 4078 or 020 8438 0844

# **Meet the Finance team**

Meet two more members of our Finance team...

Tom O'Riordan, Senior Finance Business Partner

Tom is responsible for the organisation's reporting requirements, budget setting and performance analysis. His role is to support budget holders with the information they need to make informed decisions as well as providing analysis of financial trends, and how these fit with the organisation's strategic direction.

#### Robin Hurd, Head of Finance

Robin oversees the running of the Finance team. He has been with the MS Society for 18 years having held a number of roles within the team including setting up a section to support our groups on their finances. His current role sees him co-ordinating the team, ensuring trustees and senior management receive appropriate financial information to make decisions and ensuring the organisation meets its statutory obligations. He's interested to hear from any of our volunteers on ideas on how we can manage finances better or feedback on how the team is performing.

- Audience: All
- Action: Note
- Contact: Robin Hurd, Head of Finance robin.hurd@mssociety.org.uk 020 8438 0775



## **Grants update**

The Health and Wellbeing Grant (HWG) successfully launched in January. The first HWG Grants Panel, which is made up of volunteers, took place in February where 47 grants of over £500 were awarded. MS National Centre also awarded 63 Health and Wellbeing small grants of under £500 and 18 Carers Grants in the first three months of 2017.

All panel meeting dates and associated deadlines for submitting HWG applications is available at volunteers.mssociety.org.uk/ national-grant-funds. You can also find information and guidelines on the new grant application form.

We've been working with local groups to support you with the new process, and will continue to do so. If you'd like to start using the new Health and Wellbeing grant application, please contact the Grants team. Further discussion on how this new grant programme will be rolled out at a local level will be available at the Spring Volunteer Forums taking place this month and June. If you have any queries please do get in touch.

- Audience: All
- Action: Share
- Contact: Grants team grants@mssociety.org.uk

**For England** 

# Award for local community group!

We're delighted to let you know that in March Joyce Unthank, from the South East Essex group, was presented with the 'Community Group of the Year 2017' Award from Castle Point Council, by the Mayor of Canvey Island, in recognition of her hard work and dedication successfully running the MS Wednesday Club for many years.

Joyce has been involved in running the club on Canvey Island for over 20 years. Throughout those years she's seen lots of changes. Over the last 18 months they've had a 50% rise in regular attendees, and this is largely because word has now spread of the warm welcome that awaits new members.

The group are putting the word out via local doctors surgeries and health centres, along with MS nurses at both Basildon and Southend Hospitals. They hope to increase attendance even further to support them in raising awareness of MS and all they do to support local people.

Congratulations Joyce, and thank you for all your ongoing hard work to support people affected by MS!

Audience: England

Action: Note

# **Awards for All**

Awards for All offer grants of up to £10,000 for activities aiming to improve the lives of local people and neighbourhoods. You can apply any time and groups with smaller incomes are looked on favourably. It's recommended that applications are submitted at least four months before you want your project to start.

If you're interested in making an application please do get in touch with your Area Fundraiser and LNO, both of whom can support you with the application.

Our Huntingdon & District group was recently awarded a grant of £9,196 to help develop exercise and wellbeing opportunities across Huntingdonshire. They worked closely with health professionals, service providers and their local MS Therapy Centre to help identify local need. The award will help to deliver a range of services including seated exercise, healing yoga, music therapy and Nordic walking. The group hope to provide a wide range of activities to suit all levels of ability, at different locations and times, to meet as many people's needs as possible.

More information on Awards for All can be found at https://www.biglotteryfund.org.uk/ funding/Awards-For-All

- Audience: England
- Action: Share
- Contact: Your Area Fundraiser/LNO



#### New neuro physio service

We're delighted to announce that **Rachel Flinn** has been appointed as a Neuro Physiotherapist based at our Resource Centre in Belfast. Working at the MS Society two days a week, Rachel is able to offer 1-to-1 appointments and devise programs suitable to each individual's needs.

Rachel has a BSc Hons in Physiotherapy and has completed extensive post graduate training in Bobath Concept of Rehabilitation, Motor Relearning, Constraint-induced Therapy and Pilates including Neuro Pilates. Having specialised in Neurological Physiotherapy for many years, Rachel has amassed expertise covering MS, Stroke, Parkinson's and Movement Disorders.

Neuro physiotherapy is one of a number of services and classes available from the Resource Centre including counselling, complementary therapies, art classes, yoga and Pilates.

- Audience: Northern Ireland
- Action: Share
- Contact: Northern Ireland reception nireception@mssociety.org.uk 028 90 802 802

# **Campaign pilot**

Northern Ireland has been chosen as a pilot site for a new volunteer campaigning role within the MS Society. We've now recruited four National Campaigners who'll be working on the next stage of the 'End the Wait' campaign, to address excessive waiting times people with MS face in Northern Ireland. The new campaigners have been inducted and completed some media training with Sarah Travers from Bespoke Communications (pictured). The campaigners will be drawing up a campaign plan, organising events and getting active in changing things for the better for people living with MS.



The group still has room for interested campaigners. If you'd like to get involved and help reduce waiting times and improve services for people living with MS in Northern Ireland or would like more information please contact Marian on the details below.

- Audience: Northern Ireland
- Action: Share
- Contact: Marian Mawhinney, LNO Northern Ireland (North) marian.mawhinney@mssociety.org.uk

**For Northern Ireland** 

#### **Fundraising events**

Our **Slieve Donard Moonlight Walk** is back! Taking place on the evening of **12 August** through to the following morning, it's a fantastic and unique way to experience Northern Ireland's highest peak. Walkers begin their ascent around 8.00pm and arrive back from 1.30am, led by qualified mountain guides.

Also coming up is our **Lagan Zip Slide** on **19 and 20 August**. This ever popular event proves to be a real winner with our supporters so encourage people to book early to avoid missing out.

For the first time we're organising an **abseil** at Belfast Castle, on **1October**. As well as being a fabulous setting with views over Belfast Lough and towards the Mournes, this is a great way to enjoy one of Northern Ireland's iconic buildings from a unique perspective.

**Cake Break** is ongoing with information available at www.cakebreak.org.uk Let's hope the weather is good and summer can be filled with alfresco Cake Break fun, while raising 'some dough'.

Please share with your group members and encourage people to get involved, and raise money to help stop MS.

- Audience: Northern Ireland
- Action: Share
- Contact: Northern Ireland Fundraising team fundraisingni@mssociety.org.uk 028 90 802 802

# **Upcoming Events**

#### Family Fun Day – Saturday 10 June Ormeau Park, Belfast

Come along to our Family Fun Day at Ormeau Park, Belfast on Saturday 10 June. The fun starts at 12 noon and will run through to 3pm. We'll have lots of attractions including bouncy castles, face painting, lots of games and family fun for everyone.

#### Carers Heath and Well Being – 9 June and 13 June The Resource Centre, Belfast

Calling all carers! Come and join us on Friday 9 June and/or Tuesday 13 June to enjoy a relaxing morning, chatting over refreshments and participating in a meditation and relaxation class, along with a lovely buffet lunch. Information and support will be available from Carers NI and MS Society staff.

We'll also be holding a **Living with MS** event at **Crowne Plaza, Shaws Bridge (formerly Ramada Hotel) on Saturday 16 September** – save the date! Living with MS is the biggest event of its kind in Northern Ireland, bringing much of the MS community together – we'd love to see you there.

- Audience: Northern Ireland
- Action: Share
- Contact: Northern Ireland reception, nireception@mssociety.org.uk 028 90 802 802

**For Scotland** 

# Upcoming fundraising events

Could you, your friends or family climb the UK's highest mountain at night?

On **25 and 26 August** we're offering fundraisers the chance to climb Ben Nevis overnight, with only a headtorch and the moon as a guide...

One of our mountain leaders said "There's something very special about wild places in the dark, the sense of peace is incomparable – a fantastic way to get away from the pace of modern life!"

Last year, 87 daring walkers took on our challenge and raised an amazing £59,000 to help stop MS. It was our first ever night hike and we're very excited to be running the event again this year!

#### Take to the skies

Our tandem skydivers jump from a plane 10,000 feet high and free-fall for 30 seconds at a speed of 120mph.

We've just 24 places for the skydive, on **Saturday 24 June** at Fife Airport, Glenrothes. Places will go quickly, so early booking is recommended to turn the sky orange and help stop MS.

#### Mr and Mrs Motivators needed!

We have 100 amazing runners taking on the Edinburgh Marathon Festival on **27 and 28 May** – and we need you to be an MS superstar and help cheer them on. Taking on a marathon is a tough challenge, but there's nothing like cheers of encouragement from our fantastic **#MSSuperstar** team to spur our participants towards the finish line.

We'll cover expenses, provide lunch and all the orange goodies needed to be top cheerers!

Please share information about upcoming events with your members and get in touch if you'd be interested in taking part or volunteering to cheer.

- Audience: Scotland
- Action: Share
- Contact: Scotland Fundraising team msfundraising@mssociety.org.uk 0131 335 4050

#### New group resource

Could your local services make use of a handy postcard with the details of our MS Helpline and local support? They're ideal for MS nurses to give to people who've been newly diagnosed, but could also be distributed to GPs and other relevant professionals.

To find out more, please contact Tracey Harrison on the details below.

- Audience: Scotland
- Action: Share
- Contact: Tracey Harrison, LNO tracey.harrison@mssociety.org.uk 0131 335 4054



# **Big Lottery Fund Project**

Our exciting new project: 'My MS – My Rights, My Choices' started this month.

The project will provide a dedicated information, advice and advocacy service for people affected by MS in Wales.

Our research has shown that over half the total number of people living with MS in Wales are unable to manage their condition or advocate on their own behalf through a lack of information, advice and support. This has had a profound impact on their health and wellbeing.

In addition to the Big Lottery Fund grant of £447,293 for the three year project, MS Society Cymru has been awarded a Masonic Charitable Foundation grant of £55,000.

This grant will enable us to deliver sessions on individual awareness and understanding rights and choices around health and social care, welfare benefits and employment support, and physical and emotional wellbeing.

Please help us circulate information about the project to your groups.

Our My MS – My Rights, My Choices Manager Adele and the team will be in touch in due course.

- Audience: Wales
- Action: Share
- Contact: Adele Gilmour, My MS – My Rights, My Choices Manager adele.gilmour@mssociety.org.uk

# Health and Social Care under the spotlight

This year, our health and social care services are being scrutinised and we're making sure that the voices of people affected by MS are part of it.

#### **Health & Social Care Review**

An independent panel has been appointed to review health and social care in Wales. This review will help the Welsh Government to identify important issues facing our health and social services by an examination of the current evidence.

#### **Neurological Conditions Plan**

The Welsh Government's Neurological Delivery Plan was published in April 2014 and sets out the expectations for the planning and delivery of high-quality person centred care for anyone affected by a neurological condition.

The plan is currently being refreshed and we need people living with MS to share their experiences of neurological services.

Funded by the Welsh Government, MS Society Cymru and the Wales Neurological Alliance are recruiting a Project Officer to develop a system to record the experiences of people living with neurological conditions across Wales.

#### **Social Services Act**

In the Autumn, the Wales Neurological Alliance will be circulating a survey to chart the progress of the Social Services and Well Being Act which began its implementation phase last year.

Please do all you can to encourage members to get involved in this vital work.

- Audience: Wales
- Action: Share
- Contact: Fiona McDonald, Policy, Press and Campaigns Manager, Wales fiona.mcdonald@mssociety.org.uk 029 2167 8924



## **Diary dates**

Meet the Cymru Council members! Join Cymru Council members and MS Cymru staff on the eve of each Council meeting for a drink and an opportunity to get to know about the work they do for the MS Society.

**Llandrindod Wells** – 4 August (Council meeting – 5 August)

Wrexham – 27 October (Council meeting – 28 October)

#### Other dates:

Cardiff Half Marathon – 1 October Living with MS Wrexham – 29 October

- Audience: Wales
- Action: Share
- Contact: For Cymru Council Matthew Witty, Executive Administrator Wales matthew.witty@mssociety.org.uk For fundraising enquiries – lestyn Evans, Fundraising Manager for Wales iestyn.evans@mssociety.org.uk

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

Group contributions 15/02/2017 to 04/04/2017				
Name	Earmarked Description	Earmarked	Research	General
Bedford group	Cambridge Myelin Repair Centre	£500.00		
Belfast group				£111.71
Campbeltown & District group			£3,000.00	
Colchester & District group	Cambridge Myelin Repair Centre	£3,000.00		£3,000.00
Hastings & Rother group	Progressive MS Research	£2,500.00		
Milton Keynes & District group	Helpline	£1,000.00	£1,000.00	
North Devon group			£2,000.00	
North Dorset & District group	Stem Cell Research	£2,000.00		
North Down & Ards group			£5,000.00	
Orkney group			£3,000.00	
Scarborough & District group	Cambridge Myelin Repair Centre	£2,000.00		
Wareham & Purbeck group	Cambridge Myelin Repair Centre	£2,500.00		
Wareham & Purbeck group	Stem Cell Research	£2,500.00		
Wrexham & District group	Cambridge Myelin Repair Centre	£1,500.00		
Wrexham & District group	Edinburgh Centre for Translational Research	£1,500.00		
Total		£19,000.00	£14,000.00	£3,111.71



#### Accessible caravan

The Surrey group has a two-bed accessible caravan with full veranda and wheelchair ramp access available for holiday hire based at Church Farm in Pagham, West Sussex.

The Rio Willoughby is a comfortable and stylish caravan specifically designed with the needs of wheelchair users in mind. It has a spacious lounge/diner, a kitchen with lowered work surfaces, a bathroom with walk-in shower and two bedrooms.

Church Farm is a 5\* Haven site with a great entertainment schedule and two swimming pools. For further information, please email mscaravanpagham@hotmail.co.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 www.parkdean.com. For availability ring Dave on 07793 414874 or email dandm4sc@btinternet.com.

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

# 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 both properties, please contact the Bexley & Dartford group on 0208 306 7050 or email bexley@mssociety.org.uk.

# 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.

# **DOC** 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 and advice 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 0300 500 8084 supportercare@mssociety.org.uk

**National MS Helpline** 0808 800 8000