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September 2017

# Teamspirit



Dom Thorpe, personal trainer, with participants Terry and Gabrielle taking part in new exercise videos

# **MS Active Together!**

e're launching an exciting new campaign this month called MS Active Together, which raises awareness of the benefits of physical activity for people living with MS.

To kick things off, we released a series of exercise videos co-created with Dom Thorpe (pictured above, centre), a personal trainer who's worked with people living with MS for a number of years. We know that many of you run successful exercise classes and already promote physical activity. We'd love to hear how you and your groups get active!

Find out more about MS Active Together and how you and your group can get involved on page 4.

# 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!

# Updating your personal information

In the coming months all our volunteers will be asked to update their personal information for our records.

To cover all bases, the request to update your information will be included in a number of communications but you'll only need to respond to this once. Keep an eye out for the link, coming soon!

#### Why update?

There are lots of reasons for making sure all our volunteers' details are accurate and up-to-date, including:

- ensuring you get essential information for your role
- you're able to tell us what you think in our annual volunteer survey
- we save valuable resources by always sending information to the right address
- your volunteer manager knows who to contact in case there's an emergency
- we all meet legal requirements in protecting personal information
- we can thank you!

#### What will happen with your data?

All information will be added to our database only for the purpose of processing applications, contacting you about your role and understanding our volunteers.

If you have any questions or concerns, please contact the Volunteering team.

- Audience: All
- Action: Share
- Contact: Volunteering team volunteering@mssociety.org.uk

# Membership information and data protection

The Data Protection Act legally requires us to ensure the personal data we hold about service users, members, volunteers and staff is accurate, stored securely and not kept longer than necessary. This applies to the personal details of local group members, service users and contacts.

Section A6 of our Group Handbook was recently updated and provides practical advice on how to handle personal data appropriately. Most of our local groups are already using the Portal to access their membership information and all groups need to start doing this.

When communicating with members you need to ensure you're using the Portal as the only source of contact information and not storing membership lists locally. The Portal refreshes each night so this is always the most up to date information. It keeps your members' details safe and secure. Early next year the Portal will be updated so it can securely store details of contacts who are not MS Society members.

For support using the Portal please contact Supporter Care. Information on how to get a login and start using the Portal is also available on the volunteer website.

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

**News and events** 

#### **Volunteers' Survey**

Our annual Volunteers' Survey is now available to complete at surveygizmo.com/s3/3738217/ Volunteer-survey-2017

The survey is an annual opportunity to share your thoughts on things that are working well and areas in need of improvement. Some of the questions will be the same as in previous years so we can see if we're all improving overall.

The answers in the survey help inform plans about how we can all best support volunteers.

Please encourage the volunteers in your group to have their say – the more people who share their thoughts and feelings, the better we can all respond to the results.

It'll only take a few minutes to complete and will close on Monday 16 October. Don't miss this chance to have your say!

- Audience: All
- Action: Share
- Contact: Volunteering team volunteering@mssociety.org.uk

#### Awareness talks and Living with MS events

We're excited to let you know about our Living with MS days and Awareness talks coming up around the UK this year. These events are free to attend, but booking is essential. Anyone affected by MS is welcome, whether newly diagnosed, someone who's been living with MS for some time or a carer, family member or friend. All venues are accessible for wheelchair users and those with limited mobility.

Our **Living with MS events** are day events, with lunch provided. You'll be able to join a range of workshops, learn about local MS services and keep up to date with the latest MS research.

The dates for 2017 are:

- Luton Saturday 14 October
- Wrexham Sunday 29 October
- Southampton Saturday 18 November

For more information and to book please visit mssociety.org.uk/information-days

**Awareness talks** are short talks with refreshments provided. The 2017 Awareness talks are:

- Benefits Awareness talk, Gatwick Thursday 28 September
- Benefits Awareness talk, Hereford Thursday 12 October

These events are a great opportunity to meet other people affected by MS in your local area.

- Audience: All
- Action: Share
- Contact: Conference team conferenceadmin@mssociety.org.uk

**News and events** 

#### MS Active Together... continued

MS Active Together raises awareness of the benefits of physical activity for people living with MS, and that even light exercise can make a difference.

Research shows that exercise can improve mood, mobility and muscle strength, and play a key role in helping people manage challenging MS symptoms like fatigue, balance problems and muscle spasms.

Our series of exercise videos, co-created with personal trainer Dom Thorpe, cover a range of exercises for different parts of the body and suit three levels of mobility:

- Level 1 little or no MS symptoms
- Level 2 mild to moderate mobility
- · Level 3 wheelchair users

These videos are available at mssociety.org.uk/ MSActiveTogether and free to order on DVD through our online shop. We also hosted a Facebook Live launch event where Dom and video participants answered questions from the MS community – you can see it on our Facebook page.

We're looking for 'MS Active Together Champions' to follow our new videos and chart their journey to inspire others living with MS to get their fitness fix! If you're interested in becoming one of our Champions, please get in touch on the details below. We'll provide an exclusive guide on monitoring and recording your experience.

We know that many groups run successful exercise classes and already promote physical activity. We'd love to hear how you and your groups get active. Share your photos and stories on social media using **#MSActiveTogether**.

- Audience: All
- Action: Share
- Contact: MS Active Together team msactivetogether@msscoiety.org.uk

# Making it easier to recruit new volunteers

From this month we're piloting a new way to find and recruit new volunteers!

All vacancies will be advertised on our website and on other volunteering sites, such as Do-it.org and Charity Job, reaching new audiences.

Each advert will clearly set out what's required for the role and what support is available, with the option to apply online.

A group of local volunteers have taken part in testing the system and we received valuable feedback which we've taken back to the developers.

Volunteers will also help us pilot how it might work in practice, and what guidance and support they think will be needed. Following this feedback, the online recruitment will be rolled out to everyone in 2018.

#### If you're recruiting volunteers soon...

The volunteer website is now your one stop shop for all recruitment resources.

Each one of our new roles has its own page under 'Volunteering with us' and includes a new clearly formatted role description and welcome and induction checklist. Our welcome e-booklet is now also available in the 'Welcome' section and highlights key information for all local and national roles.

If you've been in your role for a while, you may also find these resources useful as a refresher for you and/or any volunteers you support. You can request printed copies from ssadminhelpdesk@mssociety.org.uk

If you're interested in getting involved in developing resources, please get in touch. We'd love to hear from you!

- Audience: All
- Action: Share
- Contact: Volunteering team volunteering@mssociety.org.uk

# **IIII** Research

### MS Society Tissue Bank workshops

Do you want to hear about the amazing difference the Tissue Bank makes to MS research around the world? Are you interested in finding out more about registering as a donor?

The MS Society Tissue Bank is offering information workshops to groups across the UK. Staff from the world-leading centre will visit to explain the work they do and how you can get involved.

MS is a uniquely human condition, and to understand it researchers have to study human tissue. This is made possible by people with MS donating their brain and spinal cord after they've died, in the same way organs are donated for medical use.

The workshop includes the chance to see how tissue is preserved and hear about some of the 400 MS research projects around the world that have benefited so far. There will also be an opportunity to discuss what it means to register as a donor, both for people living with MS and their families.



To find out more, please contact the MS Society Tissue Bank directly. The team are keen to meet as many members as possible, but cannot visit all groups individually. Where possible please try to arrange the event in partnership with other local groups.

- Audience: All
- Action: Share
- Contact: MS Society Tissue Bank brainbank@imperial.ac.uk 020 7594 9734

# " ' ' ' Fundraising

### **Direct Marketing update**

#### Helpline Appeal

On Saturday 19 August 50,000 of our current supporters received a direct mail appeal, raising funds for our Helpline. This appeal will also feature in eight publications throughout this month, including the Sunday Telegraph, to raise awareness of MS and engage new supporters.

#### Raffle

This October we'll be launching the Winter Raffle with a chance to win one of 20 great prizes, including our £5,000 first prize! Tickets must be returned by Friday 15 December or play online until 21 December at: **raffleentry.org.uk/ mssociety** We're aiming to raise £165,000 to support our vital work.

#### **Cards for Good Causes**

MS Society Christmas cards will be available through Cards for Good Causes again this year. Cards for Good Causes sell cards on behalf of over 250 national and local charities and manage a national network of over 300 charity Christmas card shops in temporary shops set up in sites such as churches, libraries, community centres. Find your local shop at cardsforcharity.co.uk/our-shops or shop online by visiting cardsforcharity.co.uk/shop/

#### Appeal income update

Thanks to your support we've raised, at time of going to press, around £30,000 through the July edition of *advances*. And since we launched our brand new lottery we've recruited nearly 1,000 wonderful supporters to play each week, all with a chance of winning £10,000!

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

# Host a Pumpkin Party this autumn!

Hold a Pumpkin Party this October and raise funds to help stop MS! Why not get your family, friends and colleagues round for a frighteningly fun, spectacularly spooky or devilishly delicious Pumpkin Party?

A Pumpkin Party can be anything you want it to be! Big or small, it's a great excuse for a celebration.

Here's a few of our frightful favourites:

- Halloween bake off
- pumpkin carving competition
- freaky fancy dress
- Halloween themed quiz night
- horror film night

Fundraisers, Laura and Scott Amey (pictured), held their Halloween Spooktakular in 2016 and raised over £600!

They said, "Our Pumpkin Party was a great success. We had a cake sale, games, prize raffle, disco and a fancy dress competition. Everyone got involved and played their part in a fantastic evening!"

To register your interest in holding a Pumpkin Party please get in touch on the details below. And please share with your members.

Let's get together and give MS a fright!

- Audience: All
- Action: Share
- Contact: Fundraising team fundraising@mssociety.org.uk



#### Team**spirit**

For group volunteers and national support group committee members

# 'I Fundraising

### **New fundraising resources**

There are three new fundraising resources now available on the volunteer website. These aim to help you develop new ideas for fundraising activities that meet external regulations.

- A new presentation and podcast cover what the fundraising standards are, the difference between fundraising 'in aid of' and 'on behalf of', and our Supporter Promise. Area Fundraisers, Andy Jarrett and Katie Bruce, tell us about how to apply these crucial standards. You can view it under 'Fundraising Standards'. There is also information in the Group Handbook.
- 2. A presentation featuring the inspirational story of the Booths, who've been fundraising since 2011. Their 10in10 event has grown from strength to strength welcoming 60 walkers when they first started, to over 500 walkers this year. This presentation includes two videos telling their story and how they've made this annual event a success. You can view it under 'Effective fundraising'.
- 3. Planning is another topic we explore. Fundraisers Russell and lestyn share their experiences of working with volunteers and supporters in planning successful fundraising activities, under '**Fundraising basics**'.
  - Audience: All
  - Action: Share
  - Contact: Fundraising team fundraising@mssociety.org.uk

#### Bexley and Dartford group are Sainsbury's Local Charity of the Year

We're delighted to let you know that our Bexley and Dartford group have been chosen as Crayford Sainsbury's Local Charity of the Year, as voted by the community online and instore. The group launched their partnership with the supermarket by holding a fundraising event in the store in early August.

The group originally applied to be considered in 2016 and were successfully shortlisted to the final three but came second. Undeterred, they reapplied this year and are keen to spread the word that persistence can pay off!

Sainsbury's run this scheme annually so if your group would like to apply for 2018 keep an eye on the website at **sainsburyslocalcharity.co.uk/** If you'd like to apply and need support with your application please contact your LNO.

- Audience: All
- Action: Share
- Contact: Your LNO



#### New pound coin

As you may be aware, at midnight on 15 October 2017 we bid farewell to the old, round £1 coin, as it will lose its legal tender status.

The good news is that the new 12 sided coins are lighter than the old, weighing just 8.75g and thinner at 2.8mm – so lighter trips to the bank for everyone!

In preparation for the change on 15 October, please ensure that you bank any coins now to avoid any loss of funds. After this date the old coins will need to be deposited directly with the bank, but this will only be a temporary arrangement.

We'd be really grateful if you could do the following as soon as possible:

- Regularly bank the money in your collection boxes. These need to be emptied, with the contents counted and total proceeds noted. It's important to ensure income from boxes can be individually traced through the accounting records. While doing this, it's a good time to check your collection box log details are up to date, including a note as to where the boxes are located.
- Don't forget petty cash! Please check whether there are any old pound coins mixed among the others and, if so, ensure the old coins are used first.
- Audience: All
- Action: Share, act
- Contact: Finance team financesupport@mssociety.org.uk

#### **Fraud awareness**

We need to ensure that we're always vigilant and careful to take steps to protect ourselves from fraud, as best we can. We need to work together to protect income and assets to the best of our ability.

Here are some simple ways in which you can help protect from fraud:

- Always bank income received promptly and record this in the accounting records as soon as possible.
- Keep any petty cash, unbanked cash and cheques in a safe or locked cash box.
- Never sign blank cheques.
- Check that your bank mandate reflects only current signatories.
- If you receive an email which appears to be from a bank (including Barclays) requesting details then please do not reply. Please forward this to the Finance team.
- Regularly review the Internal Financial Controls Checklist to ensure the essentials are being covered.

Thank you for all your help with this, and please do get in touch with the Finance team if you have any queries or concerns.

- Audience: Finance Volunteers
- Action: Note
- Contact: Finance team financesupport@mssociety.org.uk



#### **Use of funds**

We need to always be sure that we're spending our funds in line with our organisational values and in a way those who give to us expect. All our funds should be used for or to support people affected by MS.

For your group, this doesn't have to be directly. Funds could be used to generate income for the group, for admins costs or donated to other local groups or MS National Centre.

We can't spend our money on payments to other charities, despite them being good causes which may be related to MS. Payments shouldn't be made directly to research institutions or 'member only' events or services. We also shouldn't be funding services that the NHS or local authority should be providing. If you're unsure about any of these please contact your LNO, or for further details please contact the Finance team – we're here to support you.

- Audience: All
- Action: Note
- Contact: Finance team financesupport@mssociety.org.uk

### **Matched Giving**

Matched Giving (or Match Funding) is a fantastic and simple way to maximise existing fundraising!

#### What is Matched Giving?

Matched Giving is when an organisation (normally a company) matches the amount of fundraising an employee does for another organisation (normally a charity). This can either be a stipulated pledged amount, or sometimes the employer will match funds raised £ for £.

#### How can your group get involved?

You can ask supporters and fundraisers if their employer runs a Matched Giving scheme – share with your members – and encourage them to use the scheme if they can. You can also do a quick search online for companies that run Matched Giving; Sainsbury's, BP, Lloyds TSB and Barclays all run schemes.

#### How does it work?

In the majority of cases, organisations will pay Matched Giving funds directly to MS National Centre who will then allocate them according to the details provided with the donation.

When one of your fundraisers makes an application for Matched Giving through their organisation, please ask them to mention the group's name in the funds transfer. This will ensure that if the funds are received at MS National Centre, we'll be able to identify them as due to the specified group. If you receive a notification that the Matched Giving funds have been paid but you haven't yet received them please contact Treasury Support with details of the funds and we'll pay these to your group. In cases where the group name isn't mentioned on the supporting documentation, for audit purposes, we'll need written proof from the fundraiser's employer confirming the funds are due to your group.

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



### **Payment card pilot**

We're very excited to let you know that we're going to be piloting a new payment card option with some of our groups in the coming months. Following this pilot, we'll be rolling this out to all local groups soon.

The pilot will ensure that we choose a payment card option that can meet key requirements such as (but not limited to), applying overall and individual transaction spending limits, online access to your account so you can monitor and view your transactions, download statements etc. We also need to ensure that the payment card facility can provide your Coordinating team with the correct tools and level of oversight to ensure funds and assets under your group's control are administered effectively, and in line with financial regulations.

We'll keep you updated as we progress with the pilot. If you have any questions please do get in touch.

- Audience: All
- Action: Share
- Contact: Samantha More, Senior Accountant – Volunteer Groups samantha.more@mssociety.org.uk 020 8438 0779

### **Meet the Finance team**

#### Natalya Hordijon, Accountant – Volunteer Groups

Natalya joined the Finance team at the beginning of August. Although she's based in Cumbria, Natalya works very closely with the central Finance team at MS National Centre.

Natalya supports and helps volunteers with any financial queries and attends group finance visits. She'll also be involved with finance training seminars.

In her spare time Natalya enjoys hiking with her cocker spaniel (who has endless energy) and attempting to cook (sometimes successfully!) Many of you will be meeting Natalya in the coming months. In the meantime, if you have any queries or would like to get in touch please contact Natalya on the details below.

- Audience: All, especially Finance Volunteers
- Action: Note
- Contact: Natalya Hordijon, Accountant Volunteer Groups natalya.hordijon@mssociety.org.uk 0131 335 4078



#### **Grants update**

In the last edition of *Teamspirit* we let you know that we planned for all local groups who award grants to start awarding the new Health & Wellbeing Grant by October 2017.

However, you may be aware, that in May 2018 a new piece of legislation called General Data Protection Regulation (GDPR) will be coming in to effect. This will have a wide ranging impact on how we handle and process people's information. Having spoken to many of you at the Spring Volunteer Forums about this and the new scheme we've decided we need to revisit our strategy for rolling out the new grant.

At the Autumn Volunteer Forums we'll be discussing this with you further, providing more clarity on the new scheme, taking into consideration the implications of GDPR. If you're able to attend a Volunteer Forum please do so to feed in to this discussion and for more information. We'll continue to keep you updated in *Teamspirit* as we progress. If you have any questions please do get in touch.

#### **Deadlines for applications**

The application deadlines for the remaining national Grants Panel meetings of 2017 are:

- 18 September
- 20 November

Please allow at least three weeks after these dates before getting in touch to request news of the outcome. We encourage applicants to apply well before the deadline dates so we can look for funding from other sources to support applications if necessary, especially if the grants requested are above the maximum the MS Society is able to award.

- Audience: All
- Action: Share
- Contact: Grants team grants@mssociety.org.uk 0300 500 8084

# **For England**

# MS Walk is back!

On **24 September**, hundreds of MS Superstars will be turning the streets of London orange, taking part in our three accessible walks to raise funds and have a great day out with our MS community.



It's a fantastic day out for all – family and friends are welcome. As well as the walk itself, we'll be hosting a celebratory area in Battersea Park including food stands, face painting and entertainment.

With 6, 10 and 20km accessible routes to choose from, we hope you'll join us to walk, roll or stroll through London.

If you or someone you know would like to join the fun, you can sign up at mssociety.org.uk/ms-walk

Can't take part? We'd still love your help...

- Could you or someone you know volunteer as a marshal?
- Spread the word could you share our MS Walk posts on Facebook or Twitter?

We look forward to seeing lots of you there!

- Audience: England
- Action: Share, act Sign up and join in
- Contact: Community and Events team challenge@mssociety.org.uk

# **Social Care Campaign**

Next month, we'll be stepping up our campaigning on care and support. We're calling for urgent reform and a long-term funding solution for social care in England. Our campaign will also call on the Government to make sure social care reform meets the needs of working-age disabled people, as well as those of older people.

Social care was one of the top issues raised by our Campaigns Community in the lead up to the General Election in June. This is unsurprising considering the findings of our report on social care in England, published in March this year. The report found that a third of people with MS are not receiving the care and support they need, while an increasing proportion of people are having to pay for their own care or rely on unpaid carers such as family and friends. With the Government committed to a 'consultation' on social care this year, we want to make sure the voice of the MS community is heard.

Support the campaign by joining the Campaigns Community and taking action.

To find out more about the upcoming campaign or to tell us about your experiences of social care please get in touch with the Campaigns team.

- Audience: England
- Action: Share, act join the Campaigns Community
- Contact: Campaigns team campaigns@mssociety.org.uk



### Silver-Merit for Derby group at Gardeners' World Live

Congratulations to our Derby group and the horticultural staff and students at Derby College for winning a Silver-Merit Award for their entry in this year's Gardeners' World Live. Led by Mike Baldwin, the team designed and created an amazing garden to raise awareness of MS.



Titled 'Journey of Hope,' the garden symbolised the journey of those affected by MS from diagnosis to living with the condition. The garden attracted large audiences, and was an innovative way to raise awareness of MS, the MS Society and the impact of local groups.

This year is the Derby group's 60th anniversary, and the 50th anniversary of Gardeners' World. We're also partnered with the National Garden Scheme, which is celebrating its 90th birthday.

If you'd like to support the National Garden Scheme and help celebrate its 90th birthday, you can do so by sharing your beautiful nature photos at ngs.org.uk/photo/

To find a garden near you visit **ngs.org.uk** and use the 'Garden Finder' to search for gardens by location, date and accessibility.

Don't forget to also share your photo with us **@mssociety.uk** and use **#ngscomp**.

Audience: All

Action: Share

### Partnering with Citizens' Advice

In 2006 the South Devon group became aware that many people living with MS in their community were experiencing problems with benefits applications, employment and other issues. They were keen to offer support and established a partnership with Citizens' Advice to fund a Project Worker for seven hours a week.

As the need for the service increased, they were able to fund the service for 12 hours per week, but in 2011 the demand was so high they decided to apply for Lottery funding.

Kate Mitchell, Support Volunteer in South Devon, said;

"The application process was demanding, and required hard evidence to support the request... but we were thrilled to be awarded five years of funding – £95,000 – which has just now come to an end."

The partnership has been a huge success, making a real difference to people in the local area living with MS. Over the five years nearly 500 people contacted the service and successful benefit claims have amounted to £966,000. People reported less stress and anxiety as a result of the support provided, making a real difference to people's wellbeing.

Accessing the expertise of a specialist organisation has proved invaluable to people living with MS in South Devon. If you'd like to explore setting up a similar partnership in your local area please contact your LNO.

- Audience: All England
- Action: Share
- Contact: Your LNO

Team**spirit** 

For group volunteers and national support group committee members



# **For Northern Ireland**

# Coffee mornings and parents' groups

On the first Friday of every month we hold a coffee morning, from 10.30am at the Resource Centre. These mornings are an excellent opportunity for people affected by MS to come together in a nice social atmosphere.

Anyone is very welcome to drop in to these coffee mornings. So whether you're a long term volunteer, new to the MS Society, been living with MS for a long time or newly diagnosed – we'd love to see you.

A monthly parents' group also meets in the Resource Centre on the second Monday of each month. It's open to people living with MS who are parents and has proved very popular. For more information on our coffee mornings and/ or the parents' group please contact the NI reception.

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

# **Digesting Science event**

Digesting Science is an event and set of educational activities which teach 6-12 year olds about MS. It takes place at W5 in the Odyssey Arena on **4 November**. Spaces are limited, for more information please do get in touch on the details below.

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



# **For Northern Ireland**

### Benefits advice referral process

Many people affected by MS are now starting the process of transitioning from Disability Living Allowance (DLA) to Personal Independence Payment (PIP). To support people with this we've set up a referral process with the Welfare Reform Project, which is a partnership between Advice NI, Law Centre NI and Citizens' Advice.

Anyone wishing to receive specialist advice and support with the application and assessment process should contact NI reception on the details below. We'll then put them in touch with the Welfare Reform Project Manager.

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

# Fundraising

Our Fundraising team are looking for volunteers, primarily to assist at events with registration and marshalling, meeting and greeting, as well as attending and representing the MS Society at events and cheque presentations.

We have lots of events coming up and would love to hear from anyone interested in getting involved!

Coming up on **1 October** we have our brand new Belfast Castle abseil and on **8 October** our Darren Clarke Golf Day in Cookstown.

On **9 December** we have the very popular Santa Dash and Dander at Stormont estate in Belfast as well as lots of Christmas events and collections throughout the festive season.

Please do get in touch to find out more.

- Audience: Northern Ireland
- Action: Share, act get in touch
- Contact: Tom Mallon, Fundraising Manager Northern Ireland tom.mallon@mssociety.org.uk



#### Let's make some noise!

Our #MSSuperstar fundraisers take on some incredible challenges to help stop MS – and together we want to get loud about how amazing they are.

We need volunteers to help us cheer, clap and whoop our runners at the Loch Ness Marathon and the Great Scottish Run.

Please help us spread the word and join us at:

- Loch Ness Marathon, Inverness Sunday 24 September
- Great Scottish Run, Glasgow Sunday 1 October



At this year's Edinburgh Marathon, a member of the public was so impressed by our volunteer cheerers they took the time to email and tell us:

"I was blown away... the enthusiasm and support they genuinely and energetically afforded every single runner was heart-warming. The stamina and genuine, warm enthusiasm these guys had, including specifically cheering my friend on with me, was quite touching."

We provide all our cheerers with an MS Society t-shirt, cheer sticks, flags and refreshments. If you or anyone you know would be interested in getting involved please get in touch.

- Audience: Scotland
- **Action:** Share
- Contact: Rhianna Adams, Fundraising Events Assistant msfundraising@msociety.org.uk 0131 335 4063

### Tell us about your experience of accessing disease modifying therapies in Scotland

Our number one goal is to support people with MS to access effective treatments. Over recent years, we've seen a great deal of improvement with more people than ever before using a disease modifying therapy (DMT) for their relapsing MS. Of those who responded to our survey, 57% of eligible people are now receiving a DMT, compared to just 36% in 2013. But we'd like to see this figure increase. We also want to understand why some people decide to start a DMT and some don't, and to find out what barriers or influences might impact people's decisions.

To explore this, we'd like to speak to people who have relapsing remitting MS. We want to speak to people who've been taking a DMT and those who haven't, and in particular those who've made treatment decisions in the past five years.

If you'd like to take part and share your experiences, please join us at one of our focus groups – either in Glasgow on 26 October or in Dundee (date to be confirmed). It would also be great if you could help spread the word with the MS community in your area.

For further details and to register your interest please contact Mags Mackenzie or Keith Park.

- Audience: Scotland
- Action: Share
- Contact: Mags Mackenzie, External Relations Officer (Scotland – West) 0131 335 4055 or Keith Park, External Relations Officer (Costland – Fost)

(Scotland – East) 0131 335 4084 enquiries-scotland@mssociety.org.uk

Team**spirit** 

or group volunteers and national support group committee members

**For Wales** 

#### **Volunteer recruitment**

The Big Lottery Funded 'My MS My Rights My Choices' project will provide a dedicated MS information and support service in Wales – it's the first of its kind in the UK.

People living with MS helped to get the project funded and will continue to play a vital role as part of the project stakeholder group.

As part of the project we're recruiting and training 32 MS Support Volunteers from across Wales to work alongside our Information and support team to provide the personalised service to around 1,300 people living with MS. The team will provide assistance from the point of diagnosis, and help to navigate them through the complex and fragmented health, social care and welfare systems.

If you'd like to apply to be a My MS My Rights My Choices Volunteer, or for further information, please contact Adele Gilmour on the details below.

- Audience: Wales
- Action: Share
- Contact: Adele Gilmour adele.gilmour@mssociety.org.uk 020 8438 0715

# Natiluzimab and Sativex clinics in North Wales

#### Natiluzimab infusion clinic Llandudno

Betsi Cadwaladr University Health Board (BCUHB) established an infusion clinic in Llandudno Hospital two years ago. This has become very successful and there are now 10 people in North Wales who receive their Natiluzimab treatment locally – which saves the long journey to the Liverpool Walton Centre.

This is open to people living with MS, who've received infusions for longer than six months at The Walton Centre.

#### Sativex clinic

BCUHB hosts a Sativex clinic under the care of Dr Anu Jacob for people living with MS in North Wales. There are currently 15 people receiving Sativex through this clinic. If you or your members would like to learn more about this, we have publications available that explain how Sativex works and when it may be beneficial.

For further information or if you have any questions about accessing these treatments please contact Yvonne Copeland on the details below.

- Audience: Wales
- Action: Share
- Contact: Yvonne Copeland, Betsi Cadwaladr University Health Board (BCUHB) 0151 529 5645

# **For Wales**

# Progressive MS conferences in Conwy and Ceredigion

Conwy and North Denbighshire group held a successful conference in May on new and developing research on Progressive MS.

Such was the level of interest, demand exceeded the number of places available.

Presentations were given by Dr. Paolo Moraro on stem cell research and other developing research, along with Prof. Nadina Lincoln who spoke about new research in cognitive rehabilitation.

Huge thank you to all in the Conwy group for your efforts in making the conference such a success.

The Ceredigion group will be hosting a conference on Progressive MS later this year, full details will be circulated shortly.

- Audience: Wales
- Action: Share
- Contact: Urtha Felda, Local Networks and External Relations Officer (North Wales) urtha.felda@mssociety.org.uk
   020 8827 0212

# **Dates for the diary**

#### Living with MS event

• 29 October – Ramada Plaza, Wrexham

#### MS Services in North Wales campaign meetings

- 20 October Ramada Plaza, Wrexham
- **1November** Conwy Business Park, Llandudno Junction

#### **Cymru Council meetings**

Please note, in the evening prior to each Council meeting we have a little social gatherings. All are welcome – it's a nice opportunity for our volunteers, local members, staff and Council members to meet and get to know each other in a social setting.

- Saturday 28 October 2017
   Ramada Plaza, Wrexham
- Saturday 10 February 2018 Future Inns Hotel, Cardiff Bay
- Saturday 14 April 2018 Ivy Bush Royal Hotel, Carmarthen
- Saturday 11 August 2018 The Metropole Hotel, Llandrindod Wells
  - Audience: Wales
  - Action: Share
  - Contact: Matthew Witty, Executive Administrator Wales matthew.witty@mssociety.org.uk 029 3267 8921

Thank you to all groups for your contributions. They are all gratefully received. We apologise that some group contributions in February and March were missed in Teamspirit. These have been included below.

Group contributions 26/05/2017 to 26/07/2017						
Group Name	Earmarked Description	Earmarked	Research	General		
Allerdale (West Cumbria) group	Stem Cell Research	£1,000.00				
Alnwick & District group	Progressive MS Research	£1,000.00				
Ballymoney group			£10,000.00			
Bath & District group	Cambridge Myelin Repair Centre	£2,500.00				
Bath & District group	Progressive MS Alliance	£2,500.00				
Bath & District group	The role of mitochon- dria in progressive MS	£2,500.00				
Bath & District group	Simvastatin phase III Project	£2,500.00				
Bedford group	Cambridge Myelin Repair Centre	£500.00				
Belfast group				£111.71		
Berwick & Eastern Borders group			£10,000.00			
Campbeltown & District group			£3,000.00			
Colchester & District group	Cambridge Myelin Repair Centre	£3,000.00				
Colchester & District group	Stem Cell Research	£3,000.00				
Denbigh & District group	Cambridge Myelin Repair Centre	£1,000.00				
East Hertfordshire & West Essex group			£600.00			
Harrogate & District group	Helpline	£1,000.00	£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			

Team**spirit** 

For group volunteers and national support group committee members

Group contributions

Group contributions 26/05/2017 to 26/07/2017 continued						
Group Name	Earmarked Description	Earmarked	Research	General		
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				
Shetland group	Stem Cell Research	£10,000.00				
South East Essex group			£405.00			
South West Bucks group	Helpline	£1,000.00	£1,000.00			
Stratford Upon Avon & District group	Welfare	£500.00	£500.00			
Teesside group				£10,000.00		
Trafford & South West Manchester group			£1,000.00			
Trafford & South West Manchester group	Tissue Bank	£1,000.00				
Trafford & South West Manchester group	Progressive MS Research	£1,000.00				
Wareham & Purbeck group	Stem Cell Research	£2,500.00				
Wareham & Purbeck group	Cambridge Myelin Repair Centre	£2,500.00				
Wrexham & District group	Edinburgh Centre for Translational Research	£1,500.00				
Wrexham & District group	Cambridge Myelin Repair Centre	£1,500.00				
Yeovil & Sherborne District group	Stem Cell Research	£1,000.00				
Yeovil & Sherborne District group	Helpline	£750.00				
Yeovil & Sherborne District group			£2,250.00			
Total		£51,250.00	£42,755.00	£10,111.71		



#### 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 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

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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