**Teamspirit 219**

**In this document you’ll find a selection of articles taken from the July 2018 edition of Teamspirit.**

These articles have been selected for Communication Volunteers to consider for inclusion in group newsletters.

Some wording may need to be adapted for use in newsletters, as this wording is taken directly from Teamspirit.

**Articles included are:**

Lottery success for local groups!

Scrap PIP 20m rule campaign

Living with MS events

Do local groups reduce loneliness?

Partnership continues to bloom!

Direct Marketing update

MS Walk is back!

**For Northern Ireland:**

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## Lottery success for local groups!

A number of groups have successfully applied for Awards for All funding so far this year. Our Chorley, North Somerset, Rotherham and York groups have been awarded funds ranging from £5,400 to over £9,900. This will fund exercise activities and an advice project to support people living with MS in their local areas. Big congratulations to these groups!

Our IT Matters course in Northern Ireland is also funded by Awards for All – you can read more about this on page 12.

Could your group benefit from an Awards for All grant? These range from £300 to £10,000 to fund grassroots and community activity. Applications can be made at any time.

If you’d like any support and information to apply please contact your Area Fundraiser.

## Scrap PIP 20m rule campaign

The PIP (Personal Independence Payment) 20 metre rule is failing people with MS. And people are losing their independence as a result.

In June we launched the next part of our MS: Enough campaign, calling for the UK Government to scrap the PIP 20 metre rule. We’re focusing on the 20 metre rule because our research shows it’s the main reason people with MS aren’t getting the right support.

**What is the 20 metre rule?**

The rule is an assessment criteria for the higher rate mobility component of PIP. If you can walk just one step over 20 metres, which is roughly the length of two double-decker buses, you’re not eligible for higher level mobility support. This is even if you’re using aids like a walking stick.

**Launching the campaign**

On 19 June we held a launch event at Westminster, with 41 MPs in attendance.

**What are we doing and how can you help?**

We’re asking people to sign our petition, and share our campaign video to spread the word. You can see more about the campaign, watch the video and sign and share the petition at mssociety.org.uk/get-involved/campaign-withus/ms-enough/scrap-pip-20-metre-rule

You can also read our ‘PIP – A Step Too Far’ report here.

If you’d like hard copies of the petition to share please get in touch on the details below.

**How else you can support the campaign**

This summer we’re joining with 80 other organisations as part of the Disability Benefits Consortium to take the message that PIP isn’t working to MPs. If you and your group would like to meet your MP or invite them to your group to help share this message, we’d love to hear from you.

**Audience:** All

**Action:** Share

**Contact:** Campaigns team

campaigns@mssociety.org.uk

## Living with MS events

We’re excited to let you know about our Living with MS information events. Please do share dates and information with your group members.

**Who are these events for?**

* People who are newly diagnosed
* People who have lived with MS for some time
* Friends and family

**Why attend?**

* Meet others affected by MS – a great opportunity to meet people who understand and to share tips.
* Take part in interactive workshops – choose from topics such as benefits, exercise and symptom management.
* Learn about the latest MS research – hear about the latest research we’re funding and developments.
* Speak to professionals and MS Society staff – we’re here to help!
* Visit relevant exhibitors – from local and national organisations.

**Upcoming Living with MS event dates:**

* Dumfries – 14 September 2018
* Coventry – 17 November 2018
* Newport – 20 October 2018

**How to book**

Online: mssociety.org.uk/care-and-support/local-support, search ‘Living with MS event’ in the ‘Find support near me’ box.

Call: 020 8438 0891

You don’t have to commit to the whole day. Come for however long suits you. The events are free and include lunch and refreshments.

**Awareness talks**

We also run awareness talks. These shorter events focus on research or benefits developments.

**Upcoming awareness talks:**

* Somerset – 18 July
* Stratford-Upon-Avon – 6 October
* Bedford – 18 October

You can find out more at mssociety.org.uk/care-and-support/local-support

**Audience:** All

**Action:** Share

**Contact:** Conference team

conferenceadmin@mssociety.org.uk

## Do local groups reduce loneliness?

We want to better understand the role that local groups play in affecting feelings of loneliness.

Feeling lonely can impact an individual’s long term physical and mental health. We want to get a sense of people’s experiences and explore if and how local groups help reduce any sense of loneliness or social isolation.

Having this information enables us to evidence and celebrate the impact that groups are having. It also helps us develop and improve our services.

To gather this information we want to hear from people affected by MS who are currently or used to be involved with your group.

Please share this short survey with members and people who fi t in to this description, including family members and friends of people living with MS: tinyurl.com/MSSGroups18

The survey should take less than three minutes to complete. Thank you for sharing.

**Audience:** All

**Action:** Share

**Contact:** Joseph Hepworth, Service Insight and Impact Analyst

joseph.hepworth@mssociety.org.uk

020 8438 0201

**Partnership continues to bloom!**

The National Garden Scheme’s (NGS) season of opening is now well under way.

Following last year’s successful introduction, Gardens for Health Week will return this August. These are amazing opportunities for groups to visit lovely gardens free of charge. Do have a think about getting your group involved.

Many other super gardens are open at various times throughout the year or by appointment. These can provide lovely social trip opportunities for groups.

NGS’s photography competition is open until 28 August. Get creative and you could have a chance of winning a great selection of WOLF-Garten garden products.

Find out more at ngs.org.uk or contact your Area Fundraiser.

**Audience:** All

**Action:** Share

**Contact:** Your Area Fundraiser

**Direct Marketing update**

**Summer Raffle**

The Summer Raffle opened last month, with the closing date for postal entries of Friday 17 August 2018. Entries can be made online at raffleentry.org.uk/mssociety until Thursday 23 August 2018. The raffle aims to raise over £100,000. With the chance to win a top prize of £4,000, get your entries in soon!

**Summer *advances***

The summer edition of our magazine *advances* will be landing on doormats in the next few days. Supporters can read great articles about the latest MS research, campaigns, fantastic fundraisers and even a love story! We’re hoping to raise over £50,000 from our generous supporters.

**Spring Appeal**

The Spring Appeal was sent out at the end of April, asking donors to support the MS Society through a regular gift. This will help provide long-term research projects, such as our work with MRI methods, with steady, ongoing income for the future. Thanks to our amazing supporters all the targets have been beaten and we have over 400 new Direct Debits, meaning almost £40,000 extra every year!

**Audience:** All

**Action:** Share

**Contact:** Supporter Care

supportercare@mssociety.org.uk

0300 500 8084

**MS Walk is back!**

MS Walk is back for 2018. And this year, we’re delighted to be bringing MS Walk to Belfast, as well as London.

Join us on Sunday 23 September for an incredible day as we celebrate the MS community at its best. We’ll have four fully accessible routes (1, 6, 10 and 20km) to choose from. The London route takes in some of the capital’s finest views and iconic landmarks along the River Thames. In Belfast, the stunning route starts at the Titanic Quarter and finishes in Lady Dixon Park, taking in the Lagan Towpath and Botanic Gardens along the way.

You can find out more and register your interest at mssociety.org.uk/get-involved/fundraise/walking-and-trekking/ms-walk

Please help spread the word. There’ll be food, drinks and fun for all the family – we’d love to see you, whether you’d like to volunteer, take part or join us for a fun day out!

**Audience:** England and Northern Ireland

**Action:** Share

**Contact:** MS Walk, London

challenge@mssociety.org.uk

MS Walk, Belfast

eve.shearer@mssociety.org.uk

**For Northern Ireland**

**Physiotherapy**

Our Neurophysiotherapist, Rachel Flinn, is based at the Resource Centre in Belfast.

As well as running both mat based and seated Pilates, Rachel sees clients on a one to one basis. As a Neurophysiotherapist Rachel works with clients to improve quality of life through analysing movement and mobility and designing a plan of treatment to work on specific problem areas.

Appointments are available on Tuesdays and Thursdays where Rachel offers assessments and a course of treatment. Therapy can focus on mobility, balance, coordination, muscle strengthening, massage, stretching, advice and provision of a specific exercise program.

We ask for a small donation of £5. Please help spread the word with anyone who may be interested in making an appointment.

**Audience:** Northern Ireland

**Action:** Share

**Contact:** NI reception

nireception@mssociety.org.uk

028 9080 2802

**IT Matters**

As many of you will know from previous editions of Teamspirit, we’ve been running a Big Lottery ‘Awards for All’ funded programme called ‘IT Matters’. The six-week programme has already taken place in Omagh and Belfast and we’re now planning when and how to deliver the programme in other areas including Craigavon and Ballymena.

IT Matters aims to improve IT skills for volunteers and local MS support groups. Sessions cover things like social media, email and keeping safe online. The programme is also supporting volunteers in their roles to communicate more effectively, recruit new volunteers and promote the great work across the MS Society. The programme has been a big success so far.

If you’d like to find out more about IT Matters or register your interest in taking part in Craigavon or Ballymena please do get in touch.

**Audience:** Northern Ireland

**Action:** Share

**Contact:** Susan Carey, LNO

susan.carey@mssociety.org.uk

**Neurology recall at Belfast Trust**

The recall of neurology patients by the Belfast Trust is a worrying time for many. We wanted to update you on how we’re working on this issue.

**In the media**

You may have seen us in the media, commenting on the news and the recall. We’ve tried to do this in a measured and constructive way to help raise awareness of the issue and keep the concerns of people affected by MS at the forefront.

**Engaging with Trusts and decision makers**

We regularly engage with the Trusts and health decision makers anyway, however, we’ve sought and held meetings specifically on the recall with both the Belfast Trust and the Department of Health. We’re meeting with the Department of Health on a fortnightly basis for updates. Members of the NI Council of the MS Society attend these meetings to give direct feedback from people affected by MS.

We’ve also raised questions with the Belfast Trust and the Department on the events and decisions which led to the recall. We’ll continue to pursue these vigorously with both organisations and the relevant public enquiry processes.

**Providing support and information**

We’ve been working to ensure counselling and support is available at clinics, that the patient advice line continues to work well for people needing assistance while awaiting their review and that the hardworking neurologists and nurses running the extra clinics are being sufficiently supported.

If you have an experience of the recall you’d like to share or an issue you’d like us to raise please do get in touch on the details below.

**Audience:** Northern Ireland

**Action:** Share

**Contact:** NI reception

nireception@mssociety.org.uk

028 9080 2802

**For Scotland**

**Volunteer Craig to attend Queen’s Garden Party**

Living Well facilitator Craig Herbert has been volunteering with us for over a decade and was chosen for his contributions supporting people living with MS.

Craig said:

*“It’s a great honour. I have only ever considered my volunteering role with the MS Society as a way of giving something back and helping others in similar situations to those I’ve faced. Never did I think that I’d be considered to attend such a prestigious event and to represent those that I’m called to support.”*

Craig, who also volunteers with Guide Dogs Scotland, said:

*“I was lost when I was diagnosed with MS, but volunteering helped me. I’m a stronger person through my volunteering. Before I was diagnosed I wouldn’t have been able to stand in front of people and lead sessions like I do now.”*

As a Living Well Facilitator, Craig helps deliver sessions for people who are newly diagnosed with MS. Craig said:

*“Living Well with MS sessions are designed for people in the fi rst fi ve years after diagnosis. This period can be tough for people living with MS – but they can expect a friendly face and listening ear from someone who has been where they are now.”*

A big thank you to Craig and to all of our amazing volunteers!

Find out more about Living Well with MS sessions at mssociety.org.uk/living-well-ms-sessions

**Audience:** Scotland

**Action:** Share

**Two great fundraising events this autumn**

**The Great Scottish Run – 29-30 September**

This family friendly event has a fantastic atmosphere, with races from the 100m toddler dash to the half marathon. Adrian took on the run last year for his mum and aunt, and told us:

*“I decided I wanted to do something because I wanted to make their battle against MS my battle too. I want to fight for my family and help MS Society Scotland raise funds so they can continue to provide support for those affected by MS.”*

**Forth Rail Bridge Abseil – 21 October**

This adrenaline fuelled challenge sees our brave team of #MSSuperstars abseil 165ft from the iconic Forth Rail Bridge to the sandy beach below. A heart racing challenge, with stunning views across the Forth.

Would you or someone you know like to take on a new challenge? Please help spread the word, and contact us on the details below to sign up.

**Audience:** Scotland

**Action:** Share – spread the word

**Contact:** Scotland Fundraising team

msfundraising@mssociety.org.uk

0131 335 4050

**Contact:** Richard Scholey, Information Resources Editor

richard.scholey@mssociety.org.uk

**Prescribing practices in Scotland**

On World MS Day (30 May) we published our report on disease modifying treatment (DMT) prescribing practices in Scotland, Right Treatment Right Time. Overall the evidence presented in the report shows that good progress has been made in recent years. The data we gathered shows that the prescribing of DMTs has increased year on year across Scotland.

We’re also pleased that our survey of 438 people with MS in Scotland shows that most people who are taking a DMT have been pleased with the level of support and information they’ve received while making decisions about treatment.

Some key findings are:

* 87% of people who could benefi t from a DMT had been offered one
* 72% of respondents were currently taking a DMT
* 51% of people were taking a DMT within six months of diagnosis

The survey also highlighted the important roles played by the MS nurse and neurologists in providing support and information through the decision making process.

Although good progress has been made there is still room for improvement. The report details recommendations, which we’ve shared with MSPs, on how we can achieve this. Next we’ll be engaging with Health Boards to discuss how best to implement these at a local level.

Read the full report at mssociety.org.uk/getinvolved/campaign-with-us/treat-me-right/is-access-to-treatment-a-lottery

**Audience:** Scotland

**Action:** Share

**Contact:** Keith Park, External Relations Officer

keith.park@mssociety.org.uk

0131 335 4050

**Living with MS day coming to Dumfries**

We’re excited that our popular Living with MS information day will be held at Easterbrook Hall in Dumfries on Friday 14 September.

It’s a great opportunity to get up to date information from MS Society staff and MS professionals, as well as meet other people living with MS.

This event will have a special focus on health and wellbeing. In the morning, we’ll be joined by an MS researcher to hear about the latest research on health and wellbeing, exercise and lifestyle. We’ll also have practical workshops on managing fatigue, keeping active, yoga and relaxation and self-management, to name a few.

In the afternoon we’ll be joined by a researcher from the Edinburgh Centre of MS Research, who will talk about advances in MS research. You’ll also have the chance to browse a range of stands from local community groups.

**How to book**

Online: mssociety.org.uk/care-and-support/local-support, search ‘Living with MS event’ in the ‘Find support near me’ box.

Call: 020 8438 0891

You don’t have to commit to the whole day. Come for however long suits you. The events are free and include lunch and refreshments.

**Audience:** Scotland

**Action:** Share

**Contact:** Conference team

conferenceadmin@mssociety.org.uk

**For Cymru**

**Treat me Right success**

The voices of people living with MS has prompted the Welsh Government to review MS services.

For the past twelve months MS Cymru has gathered evidence from people living with the condition from all over Wales and from professionals responsible for their care.

We found that a lack of capacity and infrastructure has resulted in;

* People living with MS not being able to access vital services, treatments and the most appropriate health and social care professionals at the right time
* People living with progressive forms of the MS feel like they’re on the ‘scrap heap’
* MS Neurologists feeling they are ‘Behind the Curve’ in providing appropriate treatments

We took our concerns to the Welsh Government officials, Local Health Boards and MS Specialists.

Plans are now underway for a whole system review aiming to ensure that people living with MS in Wales have access to the right care, at the right time, in the right place and by the right professional.

We’re extremely pleased that people living with MS in Wales are being listened to. MS Cymru will be working closely with the Welsh Government, Local Health Boards and MS Teams across Wales to ensure that the promises are delivered.

We’re grateful to everyone who shared their experience with us – it’s making a difference!

**Audience:** Wales

**Action:** Share

**Contact:** Fiona McDonald, Policy, Press and Campaigns Manager (Wales)

[fiona.mcdonald@mssociety.org.uk](mailto:fiona.mcdonald@mssociety.org.uk)

02921 678924

**Active Together in South Wales**

We’re delighted to let you know that following a successful application MS Cymru has been awarded a grant of over £150k to run Active Together; a two year pilot project to promote fitness and friendship for people living with MS in Cardiff, Merthyr and Rhondda Cynon Taf.

Many people living with MS can and do remain active with their condition. However 95% of people living with MS who responded to our survey in Cardiff, Merthyr and Rhondda Cynon Taf told us that they’d like to be more physically active but face challenges in doing so. Finding suitable and accessible equipment, instructors who understand the fluctuating and progressive nature of MS and transport were some of the main issues faced.

The project will be working in partnership with the National Exercise Referral Scheme and the Physiotherapy Department in the School of Healthcare Sciences, Cardiff University to help overcome these challenges.

It will go a long way to provide the necessary support for people living with MS in the area to be more physically active and live well.

We hope that this pilot will be successful and we can develop it all over Wales.

**Audience:** Wales

**Action:** Share

**Contact:** Jessica Mansel, External Relations Officer (South and Mid Wales)

[jessica.mansel@mssociety.org.uk](mailto:jessica.mansel@mssociety.org.uk)

020 3872 8732

**Fundraising in Wales**

We still have a few Charity places available for the Cardiff Half Marathon on 7 October, but public places have now sold out. Please contact us if you or someone you know would like to reserve a place and be part of our team of MS Superstars! Don’t forget if you can’t take part, please come along and cheer on the day!

We’re delighted and grateful to have the support of Cardiff based technology company Oprema this year, who’ve chosen us as their Charity of the Year. They have a range of fundraising activities planned, including trekking Snowdonat night, a tough mudder, and a Halloween party.

A huge thank you also to staff at LexisNexis in Cardiff, who participated in the Cardiff Dragon Boat Festival and won, raising £1,725, which LexisNexis will match.

If you know of a local company who’d like to support us or for further information about Fundraising in Wales please do get in touch with Sian on the details below.

**Fundraising groups update**

In April our Cardiff Fundraising group raised almost £6,000 through their annual Black and Orange Ball in aid of the MS Society and the Merthyr RCT Support Group.

The Diablos Dynamos Fundraising group in Swansea have a number of activities planned for this year – including a Wheel and Walk in Swansea Bay, and a Sky dive.

The groups are actively seeking new members, please get in touch if you’re interested in joining them.

**Audience:** Wales

**Action:** Share

**Contact:** Sian Doward, Fundraising Manager

sian.doward@mssociety.org.uk

029 2167 8920

**My MS, My Rights, My Choices**

Reaching new members of the MS community in Wales has been a burning issue for our groups for a long time.

Thankfully the My MS My Rights My Choices project which is being funded by the Big Lottery Fund and Masonic Charitable Foundation gives us a wonderful opportunity to organise activities and reach more people.

Not only does the funding give us the capacity to deliver more events but we’re now in a great position to hold them in locations where we’ve

not been before.

Our project team of Adele, Tim, Naomi and Sophie are working alongside our LNOs to deliver the project’s activities.

Over the past year, they’ve organised several events including sessions on Grants, PIP / ESA, MS Research, Living Well with MS, Get Active and Employment.

So far 640 people have attended these events, 80% of whom are new to the MS Society. Coming up over the next few months, there’ll be a range of activities including newly diagnosed days, information days and conferences on progressive MS in South West and North West Wales.

In South East Wales we’re planning sessions on fatigue management, mindfulness, creative writing, self-defence and potentially a pottery class before the Autumn.

In North East Wales a Mindfulness course in Wrexham will run weekly from 19 September to 31 October every Wednesday evening.

**Audience:** Wales

**Action:** Share

**Contact:** My MS, My Rights, My Choices team

mymscymru@mssociety.org.uk

### Classifieds

### 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](mailto: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.

**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](http://www.parkdean.com)

For availability ring Dave on 07793 414874 or email dandm4sc@btinternet.com

### 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

**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**](mailto: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**](mailto:info@womenagainstms.org.uk)

**020 8542 1712**

**Find us online**

[**mssociety.org.uk**](http://www.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**](mailto:supportercare@mssociety.org.uk)

**National MS Helpline**

0808 800 8000

**helpline@mssociety.org.uk**

**Feedback on Teamspirit**

**teamspirit@mssociety.org.uk**