**Teamspirit 221 – Nov 2018**

**Here you’ll find the articles from the ‘Help, hope and voice’ section of Teamspirit which you may like to include in your group newsletter. We’ve included some other articles which you may also like to use, and some for our nations.**

Some articles may need to be adapted for use in newsletters, as these have been taken directly from Teamspirit. Articles included are:

**Help, hope and voice:**

* No. 10 celebrated volunteers
* Connecting through our local groups
* Here for everyone this Christmas
* Access to medicinal cannabis restricted
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**Help, hope and voice**

**No. 10 celebrates volunteers**

On 5 November 140 of our volunteers and supporters attended a reception hosted by Prime Minister, Theresa May, at Number 10 Downing Street.

The day celebrated advancements in MS research, and the incredible contribution our volunteers have made to support vital research in MS. Our Chair of Trustees, Nick Winser, spoke about the MS Society and our fantastic volunteers.

Theresa May spoke about her personal experience of MS, the MS community and progress to date. You can see her full speech at

gov.uk/government/speeches/pm-speech-atms-

society-reception-5-november-2018

Our Acting CEO, Patricia Gordon, and incoming CEO, Nick Moberly were there to meet volunteers and members of our MS community. The Prime Minister met with guests and also presented David Allen, MS Society volunteer, with the prestigious Points of Light Award in recognition of his contribution to the MS Society and our community.

**Connecting through our local groups**

“Knowing that I can talk to a diverse group of people who understand the same issues I experience is unbelievably reassuring.”

We know that our local groups make a huge difference in local communities – connecting people and ensuring no one has to face MS alone. But we wanted to understand more about this, and the impact you – our groups – have on feelings of loneliness and isolation.

You may remember that in summer we asked people living with MS to complete a survey about this. A large number of people fed-back and the results really demonstrate the hugely positive impact local groups have.

Of the 58% of people who have felt isolated, 76% of them said that being part of a local group reduced this. And similarly, from the 60% of people who identified as having feelings of loneliness, 78% of these said that being part of a local group reduced this feeling as well.

**Connecting this Christmas**

As part of our Christmas Appeal, we’re highlighting the incredible difference our services make – connecting and supporting the MS community. Read more about connecting this Christmas in the next article.

**Here for everyone this Christmas**

It’s the most wonderful time of year; when we think of others and connect with family and friends. But for some Christmas can be a difficult time of year. Together the MS community is here for everyone who needs us.

This Christmas there are so many ways you can connect.

**Donate to the Christmas Connections Appeal**

We’re hoping to raise over £200,000 to be there for people who need us most, not just at Christmas but all year round. You can get involved by donating at mssociety.org.uk/spirit

**Enter the Christmas raffle**

Enter the Christmas raffle and be in with a chance of winning £5,000! Every £1 raffle ticket you buy will be supporting people affected by MS. We’re hoping to raise over £130,000. Enter online at raffleentry.org.uk/mssociety The draw closes on 20 December.

**Christmas cards**

Nothing sends festive cheer better than a card in the post! With 10 lovely designs, our selection of Christmas cards has something for everyone. We’ve teamed up with Cards for Causes again this year so you can shop for cards online or with over 300 stores across England, Scotland and Wales visit your nearest shop. Find out more at mssociety.org.uk/get-involved/fundraise/Christmas

**Access to medicinal cannabis restricted**

Together we’ve been campaigning for cannabis for medicinal use to be legalised for people with MS who could benefit.

On 1 November, the law changed so that cannabis for medicinal use is available for prescription in the UK. This a brilliant achievement, and the

MS community played an important role in bringing about this change.

However, while specialist doctors are now able to prescribe cannabis-based treatments, we’re concerned that nothing will change in the short term for the one in 10 people with MS who could benefit.

We’re concerned that doctors are being discouraged from prescribing medicinal cannabis. New interim guidance for specialists doesn’t recommend medicinal cannabis for pain, and doesn’t address spasticity in MS – a symptom which can help be alleviated by cannabis.

We’re calling for the interim guidance on prescribing medicinal cannabis to be urgently reviewed so that access to the treatment isn’t so heavily restricted.

The National Institute for Health and Care Excellence (NICE) have started consulting on the long term guidelines for who should be able to access medicinal cannabis and we’ll be working to make sure people with MS are involved in this process.

**Ocrelizumab for primary progressive MS**

Over 21,000 people have called for a treatment for primary progressive MS to be made available.

In September, the National Institute for Health and Care Excellence (NICE) rejected ocrelizumab being made available for early primary progressive MS. This was because they think it costs too much for the benefi ts it can provide.

As a result, we launched a petition calling for the manufacturer Roche, NICE and NHS England to put patients first and agree a deal to make ocrelizumab available at a price the NHS can afford.

It didn’t take long for thousands of people to join the call and within a few weeks the petition had over 21,000 signatures. Thank you to all of you who signed the petition.

This isn’t the end. The significance of this treatment cannot be understated.

We’ll be doing everything we can to ensure the drug is available to everyone who could benefit. We want to reverse the decision, or find alternative routes to access.

To get involved and find out more please join our Campaigns Community and add your voice. Visit mssociety.org.uk/campaigns

**Runners up at BMA Awards 2018!**

Five videos on exercises that relieve MS symptoms, filmed at our Belfast office, recently won runner-up in the ‘Long-term Conditions’ category in this year’s British Medical Association’s Awards for information for patients.

Physiotherapist Rachel Flynn and volunteers Derek McCambley and Kerstin Eikenberry, all in the films, accepted the award.

You can see the films at mssociety.org.uk/Symptomsvideos

Two other resources were highly commended in their categories. Our booklet ‘Supporting someone with MS’ and the ‘Moving more with MS’ booklet and exercise DVD.

**MS Trust conference**

Earlier this month we were at the annual MS Trust conference. It’s a chance to showcase our information to around 300 MS nurses. Each year nurses take away over 3,000 of our booklets, factsheets, help cards and exercise DVDs.

**Speaking out against PIP 20 metre rule**

On 17 October the MS community went to Westminster and Whitehall to speak out against the PIP (Personal Independence Payment) 20 metre rule.

**Trapped in ‘PIPville’**

We stood outside the Houses of Parliament in PIPville – population 9,400 – representing the people with MS who’ve already lost out on the higher rate of mobility support because of the 20 metre rule.

People with MS and members of our community sent a strong message to politicians. They held placards, and were tied to their houses – demonstrating the impact of the 20m rule taking away independence and trapping people in their homes.

**Over 36,000 people call for #ScrapPIP20m**

Thank you to all of you who signed our petition. We handed in the petition – signed by 36,041 people – to the Department for Work and Pensions, calling on the Secretary of State for Work and Pensions to scrap the rule.

The PIP 20 metre rule is the main reason people with MS are losing the support they need, and the UK Government have still provided no evidence for it. As PIP continues to be rolled out, we could see a further 6,400 people living with MS lose out to higher rate mobility support. We’ll be continuing to call for this rule to be scrapped. If you’d like to support the campaign by meeting your MP, please get in touch with the Campaigns team at [campaigns@mssociety.org.uk](mailto:campaigns@mssociety.org.uk)

**Our groups and services**

**Moray group get active together!**

Our Moray Group in Scotland have launched a number of new opportunities to highlight the importance of keeping active and showcase what is already available in the local area.

The group launched **Anti-Gravity Treadmill** sessions in early October, in partnership with Move4ward, with 12 people signing up.

The treadmill, one of only three in Scotland, uses air to unweight the person enabling them to move unrestricted and pain-free which can help restore and build muscle strength, range of motion, balance, function and fitness.

A four-week **Seated Yoga** introduction course was launched at the end of September, with 10 people registering to take part. With the help of our service starter-kit for yoga, the group identified a qualified and experienced teacher and venue.

The Moray group also worked with their local Curling Development Club and Moray Leisure to host an inclusive **Curling** taster session on 30 October with a four-week beginner course offered for anyone who wants to take it further.

And as if that wasn’t enough they’re hoping to plan a ‘family day’ which will focus on physical activity in mid-2019.

Keep up with the group’s activities by following their Facebook page @MSSocietyMoray

**MS Helpline named Helpline of the Year!**

“We’re incredibly proud of the Helpline team, and it’s fantastic that they’ve been recognised in this way.”

Ed Holloway, our Executive Director of Services and Support

Our fantastic team of volunteers and staff in the MS Helpline have won Helpline of the Year 2018 in the Helpline Partnership Awards.

Our Helpline, which took more than 18,000 calls last year, was recognised for the significant contribution made to the helpline sector and the wellbeing of those who use the service.

The Helpline was also awarded second place in Helpline Innovation of the Year and volunteer, Aleks deGromoboy, won third place for Volunteer of the Year.

Ed Holloway went on to say,

“Our dedicated staff and volunteers make a real difference to people with MS, their friends and families, and over the past year they’ve introduced more flexible ways for people to get in touch, including on social media.”

Abigail Stidston, Senior Helpline Support Officer said:

“The Helpline are delighted to have received this recognition - it’s hugely important to use. We have a fantastic team of staff and volunteers who are always striving to provide the best support to people affected by MS.”

Our MS Helpline is open Monday to Friday, 9am to 7pm except bank holidays. It’s free to call from landlines and mobiles within the UK.

Huge congratulations and thanks to the MS Helpline team!

**For England**

**Talking social care with the Care Minister**

In September, people living with MS and other long-term conditions met with Care Minister Caroline Dinenage to discuss social care funding in England.

Right now, 1 in 3 people with MS aren’t getting the care and support they need with essential everyday activities like washing, dressing and eating.

We’ve been calling for the Government to provide urgent funding, alongside long-term solutions, so people with MS get the social care

they need.

At the meeting, the Minister heard directly from people with MS about the problems they face. She acknowledged the short-term and long-term funding issues, and agreed the Government needs to take big decisions.

This was encouraging to hear, but it was disappointing to see that the Government’s subsequent Budget announcement only included £650m for social care – far from filling the £2.5bn funding gap needed to keep the care system afloat.

The next step is the Green Paper (public consultation) on social care, due before the end of 2018. This is a vital opportunity to shape the future of social care, and we’ll be ensuring the experiences of people with MS are heard loud and clear by the Government.

You can find out more and get involved in our campaigns by joining the Campaigns Community at mssociety.org.uk/campaigns

**For Northern Ireland**

**Update on the recall**

At the beginning of May the Belfast Health and Social Care Trust initiated a recall of 2,500 neurology patients after investigations into the treatment and care provided by a specific neurologist. The Trust committed to reviewing each patient within a 12 week period building extra consultant and diagnostic testing capacity in order to do so.

Throughout this time, we’ve been working hard engaging with the Belfast and Trust and the Department of Health representing both individual people affected and the wider patient group within the recall.

Unfortunately, as a result of this process, we have been informed that some people have received life-changing news up to misdiagnosis. We continue to work to ensure everyone receives the care and support they need through what has been a very difficult time. There remain many outstanding questions on the circumstances surrounding the recall and decisions made before, during and afterwards. We’ll continue to pursue answers for those affected.

As a result of the recall, a number of public inquiries have been announced. The first of these is seeking input from people who have experience of neurology services. If you’d like to submit your views on neurology provision in Northern Ireland visit neurologyinquiry.org.uk

The Department of Health has also announced a wider review of neurology which will determine the future of services and provision across Northern Ireland. We’ll play an active role in this, fighting the corner of people living with MS.

If you want further information on any of this work or want to share your own experience please get in touch with us at [nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk)

**Christmas events**

**Christmas Music for MS**

Join us on Wednesday 12 December for our Christmas Music for MS event. This festive event will take place at Riddel Hall, Stranmillis Belfast.

Enjoy the sounds of the Renaissance Choir, festive readings and the obligatory hot chocolate and mince pies. Riddel Hall is the perfect setting, a Grade 2-listed red brick building, which has been sympathetically renovated to retain many original features.

It all makes for a fantastic festive event and we’d love to see you, your family and friends on the night. Who knows the big man in the red suit might even make an appearance.

Tickets for the event are just £10 and can be obtained from our Resource Centre.

**Santa Dash and Dander**

It just wouldn’t be Christmas without our Santa Dash and Dander. Many of our supporters see the Dash and Dander as the start of their festive season.

This year it takes place on Saturday 15 December at Stormont Estate with a 10.30am start. Come along and join us for this family event where you can enjoy dressing up as Santa and then Dash or Dander up and down the Avenue. The Avenue is close to 2 miles – and you can Dash or Dander at your leisure.

This is a great event for the whole family – even the pet dog can join in, provided they are kept on a lead and dress up as Santa too. Family registration for the event is £20 for 2 adults and 2 children, additional adults are £10 and children £5. Santa suits are provided on the day along with some festive refreshments and treats for the children.

For more info get in touch with us at [nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk)

**For Scotland:**

**Fundraising next year and 2020**

We have some absolutely fantastic fundraising events organised for 2019 and 2020!

Please share these amazing opportunities with your communities and encourage people to get involved.

**Arctic Trek**

We’re thrilled to launch our fi rst ever overseas trek! In January 2020 intrepid #MSSuperstars can join our team heading from Scotland to the Arctic.

On this unique challenge fundraisers will spend three days trekking in sub-zero temperatures – pulling equipment in a pulk and battling the elements.

This incredible journey will make a huge difference in helping to stop MS and give trekkers memories of a lifetime.

**Zipslide**

Our award-nominated, fully accessible, Zipslide Zinger challenge is back for 2019. We can’t wait to see our #MSSuperstars zip through the trees in beautiful Crieff on 27 April!

**Edinburgh Marathon Festival 2019**

Places for the famous Edinburgh Marathon Festival 2019 are officially open and we are thrilled to be a Premier Affiliate Charity again this year. Come join our team on 25 or 26 May for a day you won’t forget.

**Kiltwalk**

Lace up your trainers, look out your orange top and throw on a bit of tartan for the Glasgow (28 April), Aberdeen (2 June), Dundee (18 August) or Edinburgh (15 September) Kiltwalks. Make your steps count!

For more info contact msfundraising@mssociety.org.uk

**Living Well with MS Virtual Sessions**

We were delighted to launch our Living Well with MS virtual sessions in September, with funding from the RS MacDonald Charitable Trust, to support people newly diagnosed with MS living in rural and remote parts of Scotland.

Each session consists of four modules taking place over four weeks. Participants are sent supporting materials to consider before logging in virtually each week to chat with others who are recently diagnosed with MS. The aim of our sessions is to support people in sharing their experiences, feeling more confident to set up and achieve their daily goals, understanding ‘self-management’ and learning new skills to live with the condition.

One happy participant shared her experience of taking part:

“I met some lovely people and after each meeting I felt more positive about life and the future. I learned skills on how to manage time, fatigue, stress and other aspects to make life more manageable with MS.”

We’re currently trialling the virtual sessions in Scotland and, if successful, we hope to offer them across the rest of the UK.

**For Cymru**

**Update on grants**

Since starting just over a year ago, our My MS My Rights My Choices project team have been busy supporting the MS community in Wales in a variety of ways including making grant applications.

So far, Adele, Sophie, Naomi and Tim have secured around £34,000 in grant funding for people living with MS in Wales who are in financial need.

Over £13k of this has come directly from MS Society grants. People have been granted money for items such as scooters, wheelchairs, home adaptations and accessible bikes.

We know only too well that people have less money than ever before. The grants we’re able to support people with are helping to fill the gap.

Please help share information about the My MS My Rights My Choices project to support more people.

**New Big Lottery funded project in South Wales**

Being physically active is important but for many people living with MS there is a real struggle to access opportunities.

When we surveyed people living with MS in Cardiff, Merthyr and Rhondda Cynon Taf, 95% told us that they’d like to be more physically active but are prevented from doing so. This is about to change thanks to the Big Lottery Fund.

MS Cymru has received a grant of £149, 415 to run ‘Active Together’ - a two year pilot project to promote fitness and friendship for people in Cardiff, Merthyr and Rhondda Cynon Taf. A project coordinator and administrator have been appointed and will be working closely with a steering group made up of people living with MS.

Ann Jones from Rhondda Cynon Taf was diagnosed with MS in 2001 and has been part of the project steering group. She said,

“Having properly trained instructors who know about the condition and how it can affect us will be so beneficial. We need exercise classes which adapt with a person’s MS and are tailored and bespoke, so that when we are feeling well we are encouraged to move more and take it easier when we are having an off day”.

**Fundraising in 2019**

We’re super excited about our fundraising activities coming up in 2019. From sliding down a Zip Wire in North Wales to trekking 25 or 50km along the beautiful Brecon Beacons, there’s something for everyone to get involved in.

* **8 June** – Velocity 2, Zip World
* **6 July** – TrekFest, The Brecon Beacons (25km or 50km routes)
* **15-18 August** – Wales End to End Cycling Challenge
* **Oct** (TBC) – Cardiff Half Marathon

Be part of the #MSSuperstars Cheer Squad! The MS Cymru cheering squad at this year’s Cardiff Half Marathon was one of the brightest and loudest there.

Join us at next year’s Cardiff Half and the other events listed above – help us to be even louder and cheer on our amazing #MSSuperstars

To find out more get in touch with Sian Dorward at [sian.dorward@mssociety.org.uk](mailto:sian.dorward@mssociety.org.uk)