**Teamspirit 220 – Sept 2018**

**In this document you’ll find a selection of articles from the September 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 these have been taken directly from Teamspirit.

**Articles included are:**

* Ocrelizumab rejected for primary progressive MS
* Growing our community
* Stoptober is coming…
* Cannabis for medicinal use confirmed!
* Scrap PIP 20 metre rule
* Information events
* Direct marketing update

**For England:**

* Super swimmers raise funds in Isle of Wight!

**For Northern Ireland:**

* Message from new Director for Northern Ireland
* Update on recall announcement of neurology review
* Update on the co-production of our Big Lottery bid
* IT Matters sessions

**For Scotland:**

* Ocrelizumab rejected for relapsing MS in Scotland
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**Ocrelizumab rejected for primary progressive MS**

The National Institute of Health and Care Excellence (NICE), who approve drugs to be available on the NHS in England and Wales, has rejected the use of ocrelizumab for people living with early primary progressive MS.

Ocrelizumab is a drug that, since early 2018, has a Europe-wide license to treat relapsing MS and early primary progressive MS.

However, NICE have now rejected the use of ocrelizumab for early primary progressive MS. This is because the cost of the drug is deemed too high for the benefits it can provide.

This is incredibly disappointing news for the MS community, especially as there are no disease modifying treatments for primary progressive MS available on the NHS.

But this is not the end. We’re calling for the manufacturer Roche, NICE and NHS England to put people with MS first and agree a deal to make ocrelizumab available at a price the NHS can afford.

We’ll be in discussion with all those involved in the decision and have launched a petition calling for people with primary progressive MS to be put first.

You can find out more on our website at mssociety.org.uk/ocrelizumabnews

And please sign and share the petition with your members: mssociety.org.uk/speakupforms

**Audience:** All

**Action:** Share and sign the petition

**Contact:** campaigns@mssociety.org.uk

**Growing our community**

We want to ensure that we’re providing the best possible support for people living with MS. Our MS community is hugely diverse.

Together we campaign for change, provide support and information, and drive forward progress in research. And to do this we need to be as inclusive and relevant to as many people in the MS community as possible.

**Reviewing our membership model**

We’re currently a membership organisation but, with our aim of growing the community in mind, we want to review this model. A lot’s changed since the MS Society was founded over 60 years ago. Today, people connect with us and support us in lots of different ways – through our website, social media, events, services and much more. We know that, sometimes, non-members who support us can feel excluded, or worse, are excluded – whether due to the cost or process of joining as a member. We want to ensure that we’re accessible to all, as well as remaining relevant and current.

Members are invited to vote on a resolution to give us permission to explore options of a new model and this will be discussed at our AGM on 22 September. If passed, the review will take in to consideration how we protect the membership fee income of our local groups.

If you’re a member and eligible to vote at the AGM, you’ll have received an AGM booklet with your copy of MS Matters with more information and outlining how to vote.

**Audience:** All

**Action:** Note

**Contact:** Supporter Care

supportercare@mssociety.org.uk

**Stoptober is coming…**

This year we’re getting behind Stoptober to support people with MS who smoke and want to give up.

The evidence is clearer than ever: smoking can make MS worse. It can lead to bigger lesions and more relapses, and can speed up disability progression. We want to support people with MS – because we know how hard it can be to give up smoking.

**What is Stoptober?**

Stoptober is a 28 day stop smoking challenge that encourages and supports smokers towards quitting for good. It’s based on the insight that by stopping smoking for 28 days, you’re five times more likely to be able to quit for good.

Stoptober kicks off on 1 October – our MS community will be coming together to provide support and information for people with MS who want to quit.

There’ll be space on our forum for people with MS to share experiences, and support each other. And we’ll be sharing top tips and support on our social media channels and signposting to helpful resources online. You can find out more about Stoptober at nhs.uk/Stoptober

Please share with your members and anyone you know who may want support to give up smoking.

**Audience:** All

**Action:** Share

**Contact:** Campaigns team

campaigns@mssociety.org.uk

**Cannabis for medicinal use confirmed!**

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

This July, exactly a year after we started campaigning, the Government announced that they will make cannabis for medicinal use available by prescription in the UK. Plans are to reschedule cannabis-derived medicinal products by this autumn, making them legally available.

This is amazing news, and the MS community played an important part in calling for this change.

Evidence shows cannabis for medicinal use can work for some people to relieve pain and muscle spasms in MS. While there are NHS treatments for pain and spasms, these don’t work for everyone. And Sativex, a cannabis spray, is only available on the NHS in Wales.

This means legalising cannabis for medicinal use could help thousands of people with MS who haven’t been able to find relief for their pain and muscle spasms.

It’s still unclear what the system will look like and when cannabis will actually be available for those who could benefit. Together, we’ll continue speaking up on this until people with MS who could benefit have access to this vital treatment.

**Audience:** All

**Action:** Share

**Contact:** Campaigns team

campaigns@mssociety.org.uk

**Scrap PIP 20 metre rule**

In June we launched our petition to scrap the PIP 20 metre rule, and so far thousands of you have joined the campaign.

People with MS are losing access to the support they need to live independent lives because of the 20 metre rule. Personal Independence Payment (PIP) is a benefit that’s meant to help people with MS. But the 20 metre rule means they’re not getting the support they need.

That’s why we’re campaigning for change. The campaign got off to an amazing start. 40 MPs came to our launch event in Parliament, and in just 20 days over 20,000 people signed the petition.

We’ll be handing the petition into the Department for Work and Pensions in mid-October. The more people who add their voices to the campaign, the stronger our call will be.

If you’d like to sign or share the petition, you can do this at mssociety.org.uk/scrapPIP20m

To help build pressure on the Government, we’re also looking for people to meet their MP. If you’re interested in meeting your MP or inviting them to your group, please let the Campaigns team know.

**Audience:** All

**Action:** Share

**Contact:** Campaigns team

campaigns@mssociety.org.uk

**Information events**

We’re really excited to let you know about the upcoming information events happening this year. Don’t miss out on an event near you!

**Research Awareness talks**

A member of our Research team will give an informative and inspiring talk about the research we fund and a wide range of advances in MS research such as:

* stem cell therapy
* exercise and fatigue management
* clinical trial news

Upcoming Research Awareness talks:

* Stratford-upon-Avon – 6 October 2018 mssociety.org.uk/care-and-support/localsupport/research-awareness-talk---stratford-upon-avon
* Bedford – 18 October 2018 mssociety.org.uk/care-and-support/localsupport/research-awareness-talk-bedford

**Living with MS events**

At our Living with MS days you’ll have the opportunity to:

* Take part in interactive workshops on topics such as exercise, benefits and symptom management
* Get up to date information from MS Society staff and professionals
* Visit relevant exhibitors including the MS Society’s information stand
* Meet others affected by MS

Upcoming Living with MS events:

* Newport – 20 October 2018 mssociety.org.uk/care-and support/localsupport/living-with-ms-newport
* Coventry – 17 November 2018 mssociety.org.uk/care-and support/localsupport/living-with-ms-coventry

Our events are free and include refreshments.

Please help spread the word with your members!

**Audience:** All

**Action:** Share

**Contact:** Conference and Events team

conferenceadmin@mssociety.org.uk

**Direct Marketing update**

**Christmas Cards**

Christmas has landed already with the MS Society Christmas cards on sale through Cards for Good Causes. There are 10 different designs, including two special London designs, all being sold nationwide and online to raise an expected £80,000. Check out the designs and find your local store at cardsforcharity.co.uk/our-charities/ms-society.html

**September Appeal**

Our September Appeal arrived with 35,000 supporters last weekend focussing on the importance of supporting young scientists in order to advance MS research. A reminder mailing will be going out to supporters in the next few weeks, and we’re hoping to raise almost £130,000.

**Christmas Raffle**

The Christmas Raffle opens on 8 October,and we’re hoping to raise over £145,000! The closing date for postal entries is Friday 14 December, and you can enter online at raffleentry.org.uk/mssociety until Thursday 20 December 2018. With the chance to win a top prize of £5,000, get your entries in soon!

**Audience:** All

**Action:** Share

**Contact:** Supporter Care

supportercare@mssociety.org.uk

0300 500 8084

**For England:**

**Super swimmers raise funds in Isle of Wight!**

Group volunteers, Jennie Harrod, Kathy Lakin and Lisa Addison take on a swimming challenge to support people living with MS.

In May, the annual Swimarathon in Sandown saw four teams of up to six people swimming in relay to try to win awards for the most laps swum. Each swim lasted 55 minutes. The pool was full of swimmers from midday until the last teams entered the pool at 5pm.

This year, our Isle of Wight group was chosen as one of the three local charities to receive sponsorship from participants. And not only that, the group support a Saturday Swimming Club for people with disabilities, providing funding for people with MS to attend the club. Two teams from the club entered the competition, including group volunteers Lisa, Jennie and Kathy, all of whom have MS themselves.

The two teams managed to swim the equivalent of around 3 miles in their

55 minutes – not enough to win a cup but an incredible effort for seven people with various disabilities!

A big shout out has to go to Kathy in particular – who swam around 30 lengths, having never swum a full length six weeks beforehand. An astounding achievement!

A couple of months later our three volunteers attended the presentation of the awards and cheques. The Isle of Wight group were presented with a cheque for £990 – thanks to the efforts of every swimmer who took

part on the day!

**Saturday Swimming Club**

The Club is a great success, making a big difference to people in the local area.

Jennie Harrod said, *“To see Kathy’s confidence in the water grow makes the club worthwhile, all three ladies cannot praise the activity highly enough and look forward to the weekly sessions in the pool – more members are always welcome.”*

Members pay an annual £15 ASA membership and insurance and then people with MS attend for free, with carers paying just 50p per session thanks to the IoW group’s funding!

**Audience:** England

**Action:** Share

**For Northern Ireland:**

**Message from new Director for Northern Ireland**

We’re delighted to introduce David Galloway, who has been appointed as our new Director for MS Society Northern Ireland. David will take up post this month replacing outgoing Director Patricia Gordon.

A message from David:

*“I am delighted to be joining the MS Society to lead the team in Northern Ireland.*

*I’m coming to the MS Society from the Royal National Institute of Blind People where I was Northern Ireland Director for five years and most recently have held a UK-wide role. Before that I worked at the Department of Health in Belfast where among other things I was involved in decision making about investment in disease modifying therapies and MS services.*

*On a personal note, my father-in-law had MS and that experience is still felt within the family. That was one reason why my attention was drawn to the opportunity to join the MS Society but I was mainly attracted by the Northern Ireland Director role because this charity is so clearly passionate about helping people affected by MS and improving care and treatment services. Looking in from the outside, the energy and commitment of everyone involved in the work of the MS Society stands out.*

*Of course, I know it’ll take a while to get to know everyone but I plan to get out around the country and meet people in our local groups over the coming weeks. I’m looking forward to that and I will be listening intently to what you have to say.”*

**Audience:** Northern Ireland

**Action:** Note

**Update on recall announcement of neurology review**

The recall of 2,500 neurology patients by the Belfast Trust has been a worrying time for many people affected by MS and their families.

While affected patients have now received a consultant led assessment, for some there remains additional uncertainty and further appointments will be necessary. Both staff and people affected by MS continue to work on this important issue with the Belfast Trust and the Department of Health. This includes the recall itself, the circumstances which led up to it as well as the future of neurology services in Northern Ireland.

The Health and Social Care Board has recently announced a stakeholder workshop bringing together Trust staff, MS professionals, the Department of Health and charities. We’ll attend and ensure the views and experiences of people affected by MS are heard. Additionally the Department of Health has also announced a departmental review of Neurology which will shape the future of the service. This will begin in September and again we’ll play a full and active role in ensuring the views of our community are central within this review.

If you have an experience on the recall you’d like to share or an issue you would like us to raise on the review of neurology please get in touch.

**Audience:** Northern Ireland

**Action:** Share

**Contact:** Northern Ireland reception

nireception@mssociety.org.uk

02890 802802

**Update on the co-production of our Big Lottery bid**

The MS Society NI team are currently putting together a bid for the Big Lottery Fund to develop services to support and improve the emotional health and wellbeing of people living with a diagnosis of MS in the Mid and East Antrim council area. This bid is being co-produced with people affected by MS.

After advertising across social media we were able to bring together existing volunteers from our local groups and recruit people living with MS to co-production sessions.

We want to ensure everyone’s voice is heard and have developed three co-production models for people to have their say on the service being developed; these options include attending co-production meetings, having a telephone conversation to submit views or by joining a virtual meeting via Zoom.

The co-production meetings have been going extremely well and we’ve received fantastic feedback and new ideas. Many participants said they were excited to be part the project and proud to be able to design a service for people living with MS in their local community.

Co-production meetings are ongoing in planning the next stage of the bid.

If you’d like further information please contact Paula on the details below.

**Audience:** Northern Ireland

**Action:** Share

**Contact:** Paula Mclarnon, LNO (NI – North)

paula.mclarnon@mssociety.org.uk

**IT Matters sessions**

Our Big Lottery ‘Awards for All’ funded programme ‘IT Matters’ continues…

The six-week programme has run in Omagh and Belfast. The next set of sessions will be running in the Northern Trust area. They’ll take place in Ballymena starting in October. If you’d like to take part or want further information please contact Paula.

**Audience:** Northern Ireland

**Action:** Share

**Contact:** Paula Mclarnon, LNO (NI – North)

paula.mclarnon@mssociety.org.uk

**For Scotland:**

**Ocrelizumab rejected for relapsing MS in Scotland**

In July, we were disappointed to find out that ocrelizumab had been rejected for routine use on the NHS in Scotland for people with relapsing MS.

In Scotland, the Scottish Medicines Consortium (SMC) determine whether treatments should be available. They decided that the cost of ocrelizumab was too expensive for the potential benefit, and that other treatments were more cost effective.

Encouragingly, a resubmission has already been made by the pharmaceutical company to the SMC. We hope to get a new decision by the end of 2018.

The pharmaceutical company had also put in a submission for ocrelizumab to be a treatment on the NHS for people with early primary progressive MS. Unfortunately, this has been withdrawn and won’t be going forward for assessment by the SMC at present.

We’ve been working to understand the reason behind the withdrawal of the primary progressive submission and find out about potential next steps. We want to make sure that everyone with MS has access to the right treatment at the right time.

**Update on Fampyra**

Before the end of this year the SMC will make a decision about whether the symptom management treatment Fampridine (Fampyra) will be available on the NHS in Scotland. This treatment can help with walking speed. We’ll be supporting the submission as it goes through the SMC.

**Audience:** Scotland

**Action:** Share, note

**Contact:** Scotland Campaigns team

scotlandcampaigns@mssociety.org.uk

0131 335 4050

**Focus groups on Scotland’s new social security system**

Over the autumn we’ll be running a series of short focus groups with local groups across the country, include one online. We want to be able to give the Scottish Government concrete examples of how the new Social Security Agency should operate in the best interests of the people using it.

The new agency will deliver the disability benefits that are being devolved to Scotland, including Personal Independence Payment (PIP), Disability Living Allowance (DLA) and Carers Allowance.

So we want to hear your experiences, good or bad, of the current benefits system to help us shape the guidelines and regulations that staff will have to follow in the new system.

It will be a while before the new system is up and running. But we want to make sure that when it is, it works right from the start for people living with MS.

(Please note – as we reported in the May edition of Teamspirit, the Scottish Government have indicated they will pay a supplement to Carers Allowance from late summer 2018, while the Department of Work and Pensions (DWP) will pay the main Carer’s Allowance. Once the new agency is established in Scotland it will pay all of Carers Allowance with the increase.)

Dates and venues for the focus groups are still to be confirmed, but more information will follow shortly. In the meantime, please email our Scotland Campaigns team if you have any questions.

**Audience:** Scotland

**Action:** Share

**Contact:** Scotland Campaigns team

scotlandcampaigns@mssociety.org.uk

0131 335 4050

**Scotland launch first overseas challenge**

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

On this unique challenge fundraisers will travel to Rovaniemi in Finland and spend three days trekking into the Arctic. This trek isn’t for the faint hearted – participants will be pulling equipment in a pulk (a Nordic toboggan), battling the elements while trekking in sub-zero temperatures and sleeping in tents. It’s a challenge of a lifetime!

Do you know anyone who may want to take part? Email us to find out more.

**Audience:** Scotland

**Action:** Share

**Contact:** Scotland Fundraising

msfundraising@mssociety.org.uk

**For Cymru:**

**Living with MS event in Newport**

We’re excited that our popular Living with MS information day will be held at Coldra Court on Saturday 20 October.

You’ll have the chance to hear up-to-date and relevant information from talks, workshops and exhibitors. The MS Society information stand will be there and will have lots of publications that you can take away with you.

The event will focus on health and wellbeing and you’ll be able to choose from a selection of interactive workshops. The day will kick off with an informative update on MS research.

This will include what research we’re funding and exciting developments.

This is a great opportunity to meet other people affected by MS and get to know other people in the local area.

You don’t have to commit to the whole day. Come for however long suits you. The event is free and includes refreshments. We’re really looking forward to seeing you there!

**How to book**

Online: mssociety.org.uk/care-and-support/local-support/living-with-ms-newport

Call: 020 8438 0891

**Audience:** Wales

**Action:** Share

**Contact:** Conference and Events team

conferenceadmin@mssociety.org.uk

020 8438 0891

### 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.

**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**

**Women Against MS**

Confidential support and advice for women who have MS, their carers, families, friends and employers. Currently holding two information events a year.

**info@womenagainstms.org.uk**

 **020 8542 1712**

**Find us online**

[**mssociety.org.uk**](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**

**National MS Helpline**

0808 800 8000

**helpline@mssociety.org.uk**

**Feedback on Teamspirit**

**teamspirit@mssociety.org.uk**