

One day at a time

Three young people talk
about living well with MS

Inside

All your MS
community and
research updates
now in one magazine



Issue 137
Spring 2021

I know it's been a very difficult year

for so many of you but, as spring arrives, we can be hopeful that brighter days are ahead. For our community, I believe the vaccine roll-out is a reason to be cautiously optimistic (page 8).

To bring you all our latest news and views in one place, we've combined MS Matters and Research Matters into a single magazine. We're as committed as ever to keeping MS research moving forward. On page 28, you can read about the launch of Octopus, our new clinical trials platform, which will test potential treatments for progressive MS up to three times faster. In this issue, we also look at the latest research on risk factors for MS (pages 32 to 37) and hear about the value of a single, shared vision uniting researchers to stop MS (page 40).

As society tentatively starts to open up, we need to pace ourselves and be mindful of our physical and mental health. On page 22, three young people talk about the impact MS has on their lives. They took part in our 30 under 30 campaign last year to raise awareness for our Stop MS Appeal. They remind us how important it is to take things day by day. Take care.

Nick Moberly
Chief Executive



8 Your COVID-19 vaccination experiences



21 Real life: being Deaf and living with MS

NEWS

- 8** COVID-19 vaccination experiences
- 11** MS professionals on the frontline
- 12** Local Action for MS, plus disability benefits and access to treatment in Wales
- 15** Why diversity makes us more effective
- 16** Our Scottish and Welsh election manifestos
- 17** Ozanimod approved in Scotland
- 19** Meet our new Trustees

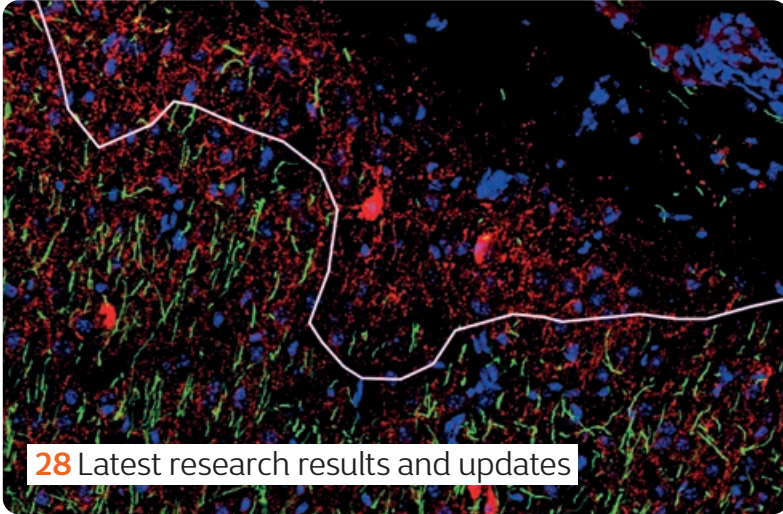
REAL LIFE

- 20** Newly diagnosed and new to the UK
- 21** The challenges of being Deaf and living with MS
- 22 COVER STORY**
How MS affects my mental health

INSIGHT

- 26** Supporting your wellbeing
- 43** Sex, relationships and MS
- 65** Discovering restorative yoga

Cover photo: Spencer Murphy



28 Latest research results and updates



58 Your fundraising stories

COMMUNITY VIEWS

- 7 Your letters
- 45 Blog spotlight: my husband... my carer?
- 46 How technology helps you
- 49 Managing MRI anxiety
- 50 When the carer goes into hospital
- 53 Getting to know you: Sandra Dodds
- 55 A new way of connecting our community
- 57 Volunteer spotlight: Jacky Davies from Bridgend
- 66 Creative corner: Diane knits new friendships

GET INVOLVED

- 58 Your fundraising stories
- 62 My MS Walk 2021
- 63 Upcoming events and our Spring Raffle

Articles signed by the authors represent their views rather than those of the MS Society. Mention or advertisement by the MS Society of products or services is not an endorsement by the MS Society, its officers or staff. The information in MS Matters is not tailored to any specific needs and it's designed for information only. No information should be taken as direct medical advice. You should assess any activity to decide if it's right for you and make sure you have the right facilities and practical support.

MS Matters is a Multiple Sclerosis Society publication ISSN 2517-6919. © Multiple Sclerosis Society 2021. Individuals or organisations wishing to reproduce, store in a retrieval system or transmit by electronic, mechanical, facsimile or other means any part of this publication should apply for permission to: MS Matters, MS Society, 372 Edgware Road, London NW2 6ND. Registered charity nos 1139257/SCO41990. Registered as a company in England and Wales 07451571.

RESEARCH

- 28 Latest research news and updates
- 32 Your questions on MS risk factors answered
- 34 Is MS written in our genes?
- 36 Could a virus trigger MS?
- 38 A new phase of myelin repair research
- 40 A global effort to stop MS

Make your donation go further

Did you know that giving direct from your salary is one of the easiest and most tax-efficient ways of donating to our work? Because your donation is taken out of your wages before tax, if you donate £5 to us, it actually only costs you £4, or even less if you're a higher rate taxpayer. Find out more at mssociety.org.uk/payroll



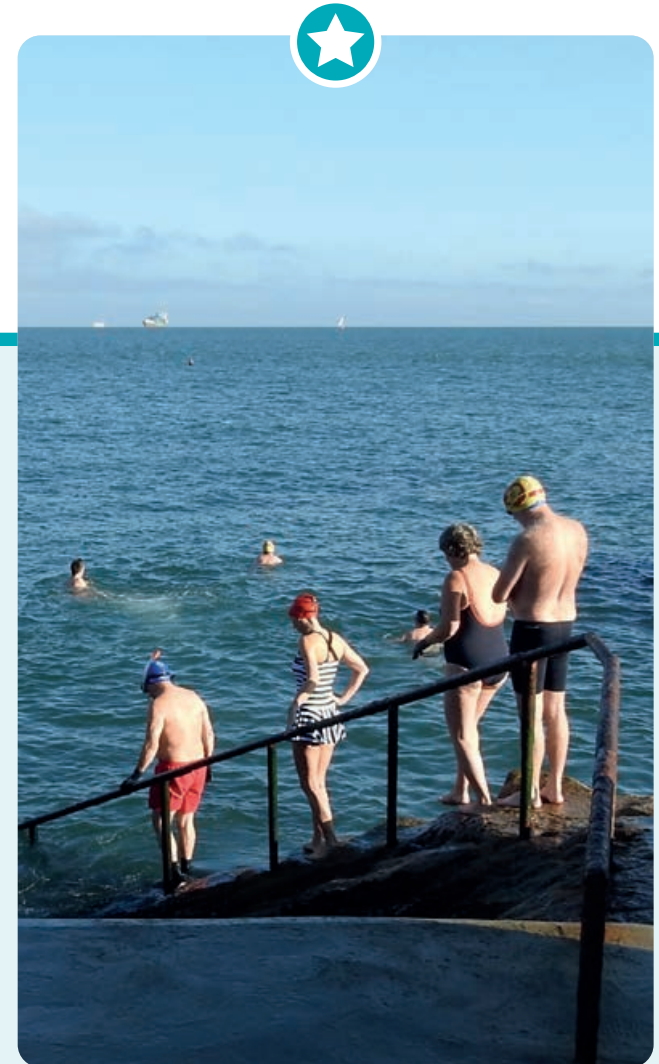
Your Letters

Cold water swimming

I was diagnosed with MS over 30 years ago. Ten years ago, I began having problems lifting my left leg, causing me to limp and stumble. This has become increasingly worse and I now require a walking stick and sometimes a walker. With the help of my brother, I go swimming in the sea. I am in the water for 40 to 50 minutes. When I get out, my condition has improved to the extent that I can run on the spot and walk unaided, with little sign of any MS symptoms. (Unfortunately, after 45 minutes my walking problem returns.) The change only happens when the water is cold. I would like to know why.

- John

MS Society - Studies have found that, for many people, MS symptoms can ease when they make their body temperature – or part of their body – colder. Special “cooling garments” can help and don’t stress the body in the way that a cold bath, shower or swim might do. Effects tend to be small and are always short-lived. Relief is often stronger the colder the temperature. No studies have explained



why cold has this effect. Possible explanations are that it might make parts of muscles less active or help signals pass easier along nerves. Everyone is different, and some people find the cold makes their symptoms feel worse. This effect is also usually temporary and should fade away when you find a comfortable temperature for you.

Helpful garden trolley

I have missed being able to do much in the garden because my balance was so bad, and I couldn’t walk on the lawn without support. Last spring, I bought a “platform hand sack truck trolley”. I can put trays of bedding plants

on it to move around, carry compost, plant pots and garden tools, and walk on the lawn with it. It has given me freedom in the garden, something we need in lockdown.

- Penny



Please share your thoughts and feedback by writing to us at mismatters@mssociety.org.uk

Cautious optimism during vaccine roll-out

As the COVID-19 vaccines are rolled out, we asked you about your vaccination experiences and thoughts on the gradual lifting of the lockdown.



Nikki:
“Having my job has given me hope and positivity.”

Personally, the last year has been a rollercoaster for me. When restaurants briefly opened in the summer, I cried my whole way through the meal terrified because I was inside with other people I didn't know, having been so careful and avoiding those I did know.

Having my job has given me hope and positivity that we are edging nearer to the end of this difficult period of our lives. I can't wait for job two. Roll on the summer when we can all start to carefully come out of our cocoons, spread our new wings and fly again.



JJ: “I was in two minds about the vaccine.”

When I was called to book my vaccine, I was in two minds and had so many questions. Is it safe for people with MS that are on a DMT drug? What are the side effects? My MS nurses really did a great job at giving me some clarity. And I decided to schedule my job.

I've recently had the AstraZeneca vaccine and the whole process was very quick and reassuring. You don't even feel it. On the same day, I had one of the side effects of the vaccine – a high temperature with cold shakes and chills. But I'm perfectly fine now.

Being vaccinated has definitely taken a massive weight off my



shoulders and given me peace of mind and a sense of security.



Dan: “I didn't notice any MS-specific side effects.”

I had some pain in the injection area, but it wasn't too bad, just more of a dull ache. I also had a mild headache, so I just took some painkillers and drank lots of water. By the second day after the injection the pain in the arm

COVID-19 vaccines and MS treatments

Our MS Society Medical Advisers have published a consensus statement about the approved COVID-19 vaccines. Here's an extract from the 12 March statement:

“Based on what we know about the way these vaccines work, and high-quality evidence from studies of other vaccines and MS, we don't think they will exacerbate MS or its symptoms, provoke a relapse, or prevent disease modifying therapies (DMTs) from being effective. We have no reason to believe any COVID-19 vaccine will be dangerous for people with MS, including those on immunosuppressive drugs.”

The vaccine might be less effective for people that have recently taken or are taking some DMTs. But they say that:

“Even a reduced response is likely to be better than none, so you should still get vaccinated even if on these therapies. And no one should stop their MS therapy unless specifically requested to do so by their MS team.”

Your MS team can discuss things with you further.



Read the full statement by MS Society Medical Advisers and find more information on COVID-19 vaccines and specific MS treatments at mssociety.org.uk/covid19-vaccines

was completely gone and so was the headache.

I didn't notice any MS-specific side effects. I did have some brain fog the day afterwards, but it's difficult to tell if this was related to the vaccine.



Samantha:
“It's OK to be cautious.”

Since the start of the year, people have been hinting at breaking

lockdown rules and “just popping round”. I am strong enough now to say, “Do not flood me.”

During this time, I have appreciated (even more) how important it is to be careful, I think we all have. Face masks or not, let's not spread germs. When things re-open, let's support local businesses and go to the pub or café instead of “popping round” unexpectedly. We can all (gradually) have a safe and enjoyable summer.



MS professionals on the frontline

We'd like to say a big thank you to MS teams and researchers for their amazing work during the pandemic.

Over the last year, MS nurses, coordinators, neurologists, researchers and many others have performed an amazing balancing act – keeping support for people with MS going while helping to tackle COVID-19.

MS professionals have been on the frontline, working on COVID-19 wards, in intensive care units and giving COVID-19 vaccinations.

They've moved mountains to maintain the best possible MS services and keep MS research moving, despite incredibly challenging circumstances.

Alison Schultz, who lives

with MS, is impressed by how her local service has adapted: "There has been no impact on my treatments. The wonderful Walton Centre has done telephone and online appointments very successfully."

In Scotland, the Lothian Therapy Centre has gone virtual to the delight of its users. One user says: "The online support and classes have been very

valuable and so positive. Well done to everyone in the team for helping us keep well."

Liz Hyland, an MS-STAT2 clinical trial participant, says: "We'd like to add our heartfelt thanks to all those MS professionals who have worked so hard to ensure people with MS are supported and our vital research continues, as well as joining the battle against COVID-19."

talk

MS Helpline

We know that not everyone has been able to access the care they need during the pandemic. Our MS Helpline is here to support you on **0808 800 8000** or **helpline@mssociety.org.uk**

LOCAL

ACTION

for MS

Do you have a great idea for a campaign you'd like to lead in your community? If so, we can give you the support you need to make it happen.

Local Action for MS is an exciting new programme to help you campaign in your local area. So whether you're frustrated about hospital parking charges or concerned about cuts to local MS services, you can make a difference.

You can find new resources and success stories from other campaigners on the Local Action for MS web area. You can also sign up as a volunteer campaigner in a new role, get training to expand your skills and connect with others working on similar issues.

You know your area best, the issues you face and the impact this has on your community. If you're not getting the services you need, speaking out really can change things.





Check out our Local Action for MS web area for resources, support and training to help you make changes in your local community. Visit mssociety.org.uk/campaign-local-area

We can't just sit back!

Chris from Cardiff is campaigning to improve access to the symptom management drug fampridine in Wales.

Chris, who was diagnosed with MS in 2018, says: "18 months ago, my consultant told me that fampridine (brand name Fampyra) could possibly help me walk better but it hadn't been approved on the NHS in Wales at that time. I saw another consultant and he prescribed it privately costing me £166 a month from my pension. The drug is helping me walk much quicker.

"In December 2019, the Welsh Health Minister announced that fampridine was to be available on the NHS in Wales. There could be hundreds of people living with MS who could benefit from taking it but delays since then mean that they can't.

"The delays are caused by a lack of capacity across Wales. Health boards need to recruit new staff to deal with new clinics. COVID-19 has made an impact too,

as the assessment needed for fampridine needs to be done face to face. It's 2021, it's not good enough that it isn't widely available across Wales."

Chris is campaigning to change this and asked us for support. He also got in touch with his Local Health Board and Mick Antoniw, his Member of the Senedd (Welsh Parliament), who contacted the Health Board and questioned the Health Minister in the Senedd. The Health Board has promised that they're working to provide a fampridine service.

Chris has shown why it's important to keep MS on the agenda of decision makers. The NHS is dealing with an unprecedented demand due the pandemic, but it's vital that when treatments like fampridine are approved, they're made available to everyone who could benefit from them without delay.

Calling for benefits that make sense

As part of the Disability Benefits Consortium (DBC), we've consistently called for disabled people on legacy benefits, like Employment and Support Allowance, to get the £20 increase given to people on Universal Credit.

Thanks to everyone who signed our petitions, wrote to your MP and helped spread the word.

We were outraged the UK Chancellor again ignored the desperate situation for many disabled people and gave an increase of less than £20 a year. We will keep speaking up together for disabled people to get this vital support.

20-metre rule in Scotland

The Scottish Government has published draft plans for Adult Disability Payment (ADP), which will replace Personal Independence Payment (PIP) in Scotland.

People who told us how disappointed they are that, despite some positive changes, the 20-metre rule was staying. We've launched a petition to demand it is scrapped.

We won't stop until disability benefits make sense for everyone with MS. Join our campaigns community at mssociety.org.uk/take-action



Read more about fampridine and treatments for balance and walking problems at mssociety.org.uk/balance-treatments

Diversity makes us more effective



We know that to speak up for everyone in the MS community, we need to make sure everyone feels represented within our organisation.

Last year, the Black Lives Matter movement shone a spotlight on discrimination and inequality. This made us pause to consider what we can do to become part of the solution. We know that we need to do more to recruit people from a wider range of backgrounds at all levels of our organisation – including our Board of Trustees.

To achieve this, we needed to make sure our pool of candidates for trustee roles was broader than it usually is. We wanted to attract people with the right skills and experience, who might not necessarily have thought of applying.

We engaged a specialist recruitment agency to help us reach people with

a connection to our cause from different networks and communities that were underrepresented on our Board. In particular, we hoped to attract candidates from Black, Asian and Minority Ethnic (BAME) backgrounds.

We're pleased that this approach was successful in attracting a more diverse pool of skilled candidates, who were put forward for election at the AGM in December 2020.

Trustee Polly Williams, who

lives with MS, was on the recruitment panel. She says: "A diverse range of skills and experiences and different ways of thinking supports stronger decision-making and gives greater flexibility to find solutions, be creative and overcome challenges.

"Going into 2021 we have a great group of Trustees who will work hard to help the MS Society achieve its goals."

Find out about our new Trustees on **page 19**.

read

What else are we doing?

We're working to increase diversity among our staff and volunteers at all levels. As part of this, we are engaging with all our staff to co-produce a new equality, diversity and inclusion strategy. Visit mssociety.org.uk/equality to find out more.

Welsh and Scottish elections: time to speak up!

The parliamentary elections in Wales and Scotland on 6 May are an opportunity to ask representatives from all political parties how they will deal with issues that affect the MS community.

Louder for MS in Scotland

More than 15,000 people are living with MS in Scotland, one of the highest rates in the world.

After speaking to people living with MS, we've put together an MS manifesto that lays out our priorities for the next Scottish Government. This includes the creation of a rights-based social security system. We're turning up the volume and asking everyone to get Louder for MS to ensure your voices are heard in Parliament.

Contact your representative and share your stories with us using the hashtag #LouderForMS. Read our manifesto at mssociety.org.uk/scotland-manifesto



I'm getting

#LouderForMS

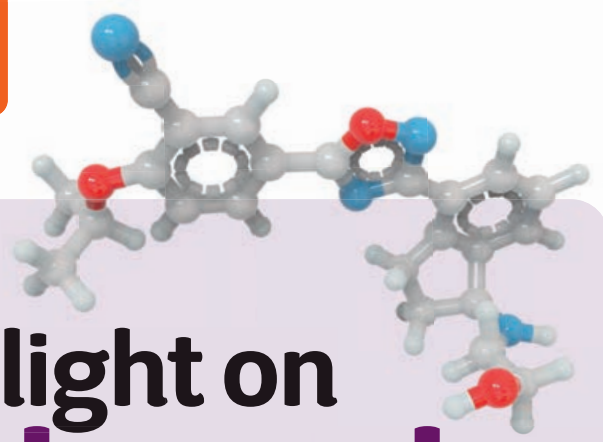
Extra powers for Northern Ireland Neurology Inquiry

Following the recall of thousands of neurology patients in Northern Ireland, an Independent Neurology Inquiry was set up in May 2018 to investigate how outpatient services in Belfast are governed.

On 11 December 2020, Robin Swann, Minister for Health, converted it into a statutory public inquiry. This gives the inquiry panel additional powers to compel witnesses to attend and compel the

production of documents.

The inquiry has heard from hundreds of patients and witnesses. It will continue to allow patients to give evidence in private despite the "public" label. The inquiry team will



Spotlight on treatments

Ozanimod, a new drug for people with relapsing MS, has been approved for use on the NHS in Scotland – the first UK nation where it will be available.

Making MS matter in Wales

Over 100,000 people live with a neurological condition in Wales. Ahead of the election, we're joining forces with the Wales Neurological Alliance to raise the issues that matter.

We're campaigning to improve capacity within the NHS to ensure that people living with MS get access to all available disease modifying therapies (DMTs) and symptom management therapies (SMTs). We're also asking the next Welsh Government to improve care and support services.

Read our manifesto at mssociety.org.uk/wales-manifesto or contact Fiona.mcdonald@mssociety.org.uk

publish recommendations they hope will be considered promptly by those responsible for healthcare in Northern Ireland.

If you are affected by the recall or have any questions, contact nireception@mssociety.org.uk

Photo: Science photo library

On 8 February 2021, the Scottish Medicines Consortium (SMC) approved ozanimod (brand name Zeposia) for people with active relapsing MS. This means it should become available on the NHS in Scotland in the coming months, if a tablet-based treatment is suitable for you or you've been asking for a tablet.

The treatment is one of a number of disease modifying therapies (DMTs), which can reduce the frequency and seriousness of relapses. As a tablet, it provides an option for people who find injectable therapies difficult to administer, widening the choice of effective treatments for people with MS in Scotland.

NICE says "no"

People with MS in the rest of the UK won't be able to access ozanimod at present. The National Institute for Health and Care Excellence (NICE) decided that, for the time being, it wouldn't recommend it for people with relapsing MS.

Ozanimod has been shown in clinical trials to reduce relapse rates compared to an older DMT called beta interferon. However, it's not yet clear what level of difference the drug makes to how fast people's MS gets worse. NICE concluded that the treatment was not cost-effective enough to be recommended.

While this initial decision is disappointing, it's not final. NICE has reversed decisions before based on evidence and/or price negotiations between the pharmaceutical company and NHS England.

As MS Matters went to print, we were seeking a change to this decision. Please keep an eye on our website for updates.



Find out more about ozanimod and disease modifying therapies at mssociety.org.uk/disease-modifying-therapies

Welcome aboard!

In January, we welcomed three new Trustees, who between them bring a wealth of experience to our Board.

Ady Dike is a business consultant who works with charities to manage change programmes that help them to become more responsive to members' needs.

"My father has Parkinson's, which like MS, affects how he moves, sleeps, feels and talks. As a carer I've long been frustrated at the quality of care he receives.

"As a Trustee I want to challenge the Board to collaborate with organisations supporting people touched by other neuro-degenerative diseases to pool our resources, make the most of our investments and reduce time to develop treatments."



Dr Shewly Choudhury is a neuroscientist by training and Head of UK Grants at the Royal Society (the UK's science academy).

"My older brother had a disabling neurological condition. I know first-hand the difference access to effective treatments, support and services can make.

"Having worked in research funding for over 15 years, I've always believed science is a force for good. The UK has one of the strongest scientific research communities in the world. I believe that by working together, we could make new treatments for progressive MS a reality this decade."



Anthony Upshall is an NHS Director who leads digital transformation programmes.

"I was diagnosed with MS in early 2019 after spending nearly 20 years with unexplained symptoms. The MS Society's online resources supported me in encouraging my clinicians to look at me holistically and eventually diagnose MS.

"Joining the Board will allow me to use my experience in digital/IT operations, strategy and transformation to improve access to and availability of services for people living with and affected by MS."



apply **Want to get involved?**

In June, we'll open recruitment for talented new Trustees, Council Chairs and Council Members to join our Board and National Councils in 2021. For more information, visit mssociety.org.uk/people or contact Danielle Walker at governance@mssociety.org.uk

Your stories

MS is different for everyone and often comes on top of other challenges.

“For the first time, I didn’t feel in control of myself”

After an unexpected diagnosis of MS, Maxim found acceptance in a new country, with help from our MS Helpline.

I was a boxer in a university team in my home city in Eastern Europe, when in 2019 the boxing federation brought in a new rule that all participants had to have a magnetic resonance imaging (MRI) scan.

It was early 2020 when I went for the scan. When I came out, I saw all the doctors crowded around me. It was frightening; for the first time, I didn’t feel in control of myself – I had to lie down.

The MS diagnosis was a shock and I developed insomnia. But I followed some basic information for newly diagnosed patients (on the MS Society website), which helped.

I had been considering

leaving my job because it wasn’t that fulfilling, but then the same week I was diagnosed, my employer offered me the chance to relocate with my role to the UK. This seemed a better option – I had read advice about avoiding any rash decisions about work.

I was relieved to learn through the MS Helpline that I would be entitled to NHS treatment, as I was considered “ordinarily resident”. It took around two and half months to navigate the system, but then I was put on Ocrevus.

What was challenging was the psychological side – the

situation with COVID-19, with my employer and with the NHS.

The diagnosis brought grief, but it also opened up opportunities. It suddenly seemed logical for me to concentrate on the things I had been putting off for years.

Some details in the article have been changed to protect Maxim’s identity.



Need information and support?

Contact our MS Helpline on **0808 800 8000**
or email helpline@mssociety.org.uk

“Language barriers have always been an issue”

Julie Gennery cares for her husband who is Deaf and lives with MS.

My husband Matthew was born profoundly Deaf and communicates by British Sign Language – BSL. At the age of 18, he was diagnosed with MS and a year later, became a full-time wheelchair user. Being Deaf made accessing information difficult and language barriers have always been an issue.

Even at diagnosis, a nurse just wrote down, “You have MS” and pushed this in front of his face.

Matthew has lived with advanced MS for nearly 35 years and requires 24-hour care, which he receives at home from myself and a team of carers. I am a sign language interpreter so access to information is better for him now. But finding appropriate care remains one of the most problematic aspects of living with MS and I worry about the future.

There are no care homes that can meet his needs and I’m currently campaigning to establish a care home for

BSL users where staff would have Deaf awareness and signing skills.

MS continues to have a huge impact on Matthew and his communication as he can no longer move his left arm or hand. For many years, he has only been able to sign with one arm which is extremely frustrating for him. My biggest fear is that he loses the use of his right

arm, making communication totally impossible.

Despite the difficult life he leads, Matthew is a very happy person and remains positive at all times. He’s a testament to how we as humans can thrive in the face of adversity and I’m extremely proud of him.

Julie has started her own petition on care provision for Deaf BSL users at mssoc.uk/Julie-petition



MS Helpline BSL service

Our MS Helpline has a BSL service for everyone who needs it. Email helpline@mssociety.org.uk for more information.

30
UNDER
30

Taking things day by day

Three young people who took part in our 30 under 30 campaign talk about their mental health and what helps them live positively with MS.

Mairead, Northern Ireland

I was diagnosed with relapsing MS in October 2019 and from then until January 2020 I was waiting at the letterbox every day for my infusions appointment to come through. My whole life revolved around starting treatment.

I'd always been outgoing and loud and talkative but, over the last year, I've found myself becoming much more introverted and on edge. I've had a diagnosed anxiety disorder for about five years, but it has increased much more. When my appointments were cancelled and postponed, I felt like I had lost control of my mental health.

I'm currently with a counsellor that's available through the MS Society in Northern Ireland, who I speak to once a week and who has MS himself. He's my source of serenity! If I'm in distress or having a panic attack I can call him.

The counselling service has been invaluable. It's open-ended, no time limits, no

short-term solutions. I've come to terms with my diagnosis and have a more positive outlook on life in general. I have coping mechanisms and I'm capable of thinking much more rationally.

I'm due to have a baby in April and me and my partner Garry are over the moon. There's so much uncertainty at the other side of childbirth. There's a risk of a relapse. I'm also worried about postnatal depression, so I'm taking things day by day.

In five years' time, I see myself being a really good mum. I want to be the kind of mum that my mum was to me.

“The counselling service has been invaluable.”



Briann, West London

I have relapsing MS, but I've learnt it's not the be all and end all. It's been a test of my inner strength.

I got diagnosed just before my 14th birthday. I lost my father and grandmother, then my grandfather, all around the same time I got ill. All that stress 100% exacerbated things with my MS. I went into a complete spiral.

My mum and I always had a very difficult relationship and I learned over time that I couldn't rely on her. I became a young person in care, then decided to move to London for education.

In my spare time I like reading, cooking, and I love being in the bath! I've got a lot of essential oils. I try to keep my body and mind as calm as possible. All of this helps me feel like I can keep my MS calm.

When I'm moving at a fast pace I just break down – my body's like yeah, I'm done! I can't work against my MS, I have to work with it. I try to

be around positive people and anything that uplifts me rather than brings me down. I believe in affirmations – the way you talk to yourself is very important.

Right now, I'm a university student, studying BA business

with entrepreneurship. I'd like to work for the council. I want to work somewhere near my house, that's reliable. I've found a national graduate development programme, so once I've completed uni that's what I'm looking to do.

“I can't work against my MS, I have to work with it.”



Our 30 under 30 campaign in December highlighted our Stop MS Appeal and the impact of MS on young people. The campaign was covered widely in national print and online media, regional publications, and on TV news and radio.

Zach, Birmingham

I was diagnosed with relapsing MS in February 2019, aged 19. It started off as a little bit of tingling in my toes. Within a few weeks, I couldn't walk without a zimmer frame because my balance was so bad, and the numbness had spread right up to my waist. I couldn't go to the toilet and had to be catheterised.

I had a lot of anxiety that sprung from the diagnosis. The fear of the unknown. When it's a condition you don't know anything about that makes things tougher. It was like a constant paranoia. Plus, I was on so many medications at that point for various things, bladder, steroids, stuff for mental health.

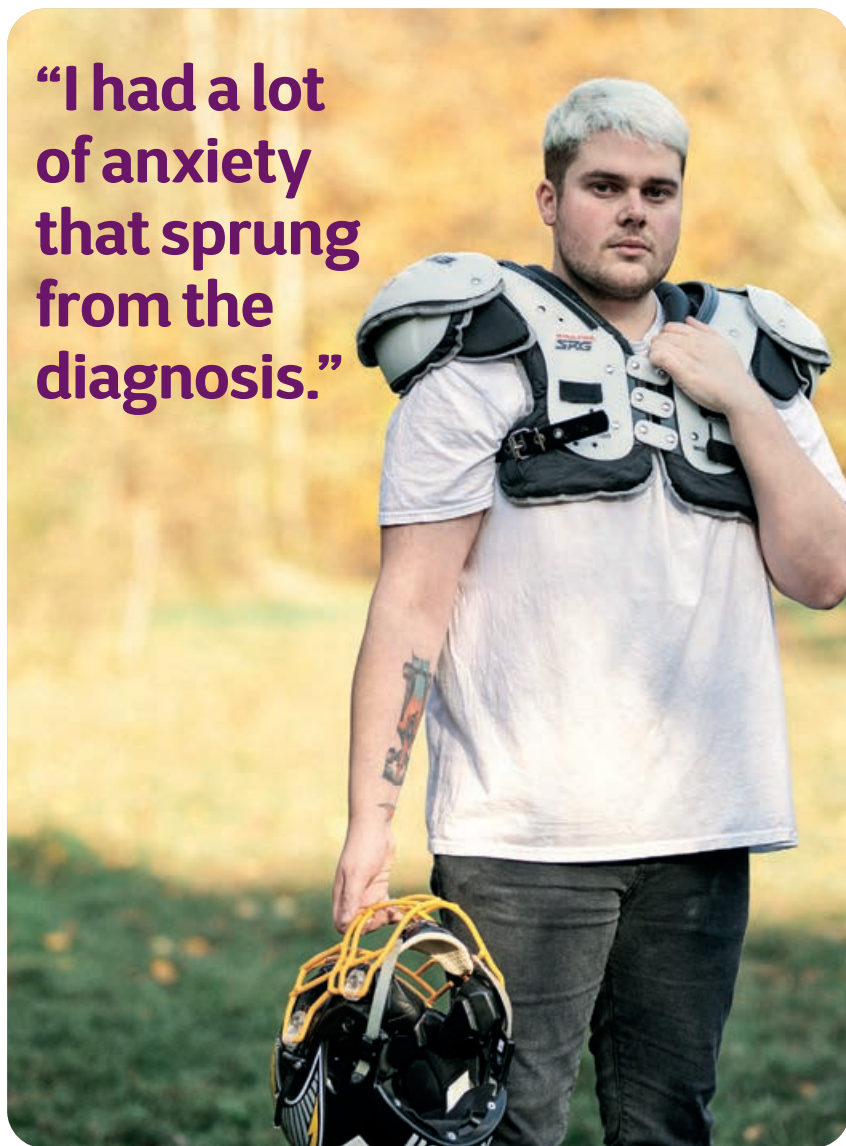
I was gradually having things taken from me that I was passionate about and that was tough. I was an American footballer for a few years and had to stop because of MS.

The worst time was my first relapse. It just cut into me, mentally and physically. Your brain goes into overdrive. My relationship with my girlfriend was taking a bit of a hit because you can't do certain stuff. With a lack of sensation, you can lose intimacy. She was absolutely amazing, though. We've been together for three years and she's stuck with me through all of this.

I work in pensions and finance now. Work is going well, and they're really impressed with the work I'm doing. I didn't let it hold me back at all. I'd love to get a job in London and carry on working my way up the ladder.

Spencer Murphy

“I had a lot of anxiety that sprung from the diagnosis.”



Information and support

Our UK-wide MS Helpline offers emotional support and information to anyone affected by MS and can let you know how you might find counselling near you. Call **0808 800 8000** or email helpline@mssociety.org.uk

Our website has information on mental health (mssociety.org.uk/mental-health), pregnancy (mssociety.org.uk/pregnancy-and-birth) and sex and relationships (mssociety.org.uk/sex-and-relationships). If you're worried about your mental health or other issues in this article, you can also speak to your GP or MS team.

Support for your wellbeing

We know the last year has been tough. Here are some of the ways we're continuing to support your mental health and wellbeing.

It's good to talk: our new Befriending service

Social isolation can be tough. We know from our research that loneliness and isolation affect three in five people with MS.

Our new Befriending service gives you the opportunity to have a weekly phone call with a volunteer for 12 weeks. It's for anyone affected by MS, including carers, family and friends.

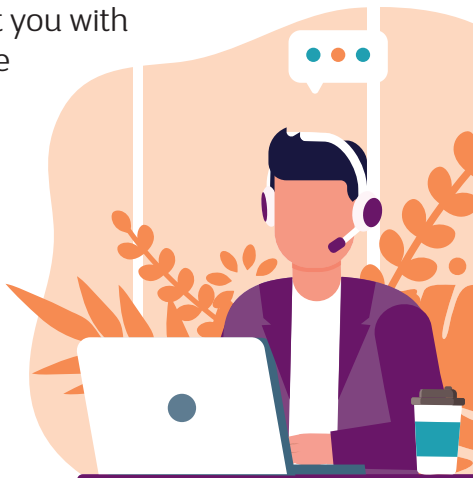
"[My befriending volunteer] is great and has really helped me stay sane and safe," says one service user. "I've had a lot going on in my personal life this year and the support from the MS Society has been fantastic."

How does it work?

Once you've signed up, we'll match you with a befriending volunteer. They'll call you every week for 12 weeks and you can chat about anything you want.

Please note we currently have a waiting list for new sign ups. We'll contact you with more information when we receive your completed registration form.

To sign up, visit mssociety.org.uk/befriending or call our MS Helpline on **0808 800 8000**. Please email us at Befriending@mssociety.org.uk if you have any questions.



Volunteer in Tayside



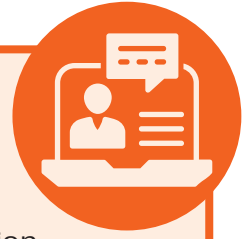
Do you have a couple of hours a week to spare? Our My MS, My Way: Tayside support service is looking for volunteers who are living with MS to help deliver a new peer support programme. The service is for people in Dundee, Angus, Perth and Kinross.

The programme will offer people at any stage of their MS journey emotional support through virtual sessions. It will match people living with MS with someone who has similar interests and experiences.

As a volunteer, you'd help people with MS feel less isolated, more confident about talking about their condition, and better able to manage their health and wellbeing. This role is flexible and full training will be provided.

The My MS, My Way: Tayside project also offers information webinars, wellbeing sessions, and one-to-one counselling support.

Find out more: mymsmyway@mssociety.org.uk



Join our webinar on mental health

Our Living Well team has created a series of webinars so you can easily access expert information on a range of health and wellbeing topics in your home.

In April, we're focusing on the importance of looking after your mental health.

Hannah MacIntosh, a person-centred therapist with experience in occupational health and community mental health, is leading our webinar on mental wellbeing. Join us for tips on how you can be more resilient and create a daily routine that works for you.

Rachael Tomlinson has attended many of our information webinars, including sessions on COVID-19, nutrition, meditation, fatigue and exercise.

Rachael, who has primary progressive MS, says: "It was reassuring listening to experts. They know what our needs are, and you can ask questions too!"

Our **Building resilience and good mental health** webinar is on 22 April at 7pm. Find out more: mssociety.org.uk/webinar-mental-health

Discovering meditation in Scotland

In Scotland, we've been providing anyone affected by MS with wellbeing support during the pandemic through our Wellbeing Hub.

This includes one-to-one counselling support, four-week mindfulness courses and meditation courses.

Catherine Symington, who is living with primary progressive MS, has attended our meditation course. She says: "I found myself feeling lonely at times and my mood has been low at points. Having the classes made a big difference.

"I'm usually not great at relaxing but I left the meditation sessions feeling calmer, more focused and had more energy.

"Jacqueline, the session leader, was really good at explaining meditation and how practising it can help you. I think the Wellbeing Hub is a terrific service and I've found the meditation sessions hugely beneficial."

Email wellbeingScotland@mssociety.org.uk or call **0131 335 4050** to find out more. You can read about mindfulness and MS, and listen to our podcast, at mssociety.org.uk/mindfulness-and-ms



talk

Further support

Our MS Helpline offers emotional support. Contact **0808 800 8000** or helpline@mssociety.org.uk, Monday to Friday, 9am to 7pm except bank holidays. And Samaritans offer support 24 hours a day on **116 123** or at jo@samaritans.org

Research **round up**

We take a look at some of the latest updates from our fabulous MS Society-funded researchers.

Octopus gets the go ahead

In March, we announced our commitment to raise £12.9 million for a new approach to clinical trials for progressive MS - Octopus. This is a huge step. Octopus' unique design will revolutionise the way we test treatments for primary and secondary progressive MS, delivering answers much more quickly than traditional trials.

A groundbreaking design

Octopus is what's known as a "clinical trials platform". Instead of separate trials for each potential treatment, Octopus' design means we'll be able to test multiple treatments at once against a single placebo (inactive treatment).

This combines with the groundbreaking approach of a so-called "interim analysis". Partway through the trial, we'll use

“This is a huge step-change compared to previous research and it is extraordinarily exciting!”

Professor Jeremy Chataway (pictured right)



magnetic resonance imaging (MRI) to get an idea of whether each drug is looking promising. Successful drugs can move seamlessly onto the next stage, with hundreds more people joining the existing participants. Drugs that don't look promising will be dropped from the trial so we don't waste time on treatments that are unlikely to stop disability getting worse.

Preparing for the first participants

This has never been done before in MS and it's taken a lot of work to get to this point. But now the team, headed up by Professors Jeremy Chataway and Max Parmar from University College London, are busy getting Octopus ready for the first participants to enrol.

A group of experts - including doctors, scientists and people affected by MS - has drawn up a list of drugs that have shown promise in the lab and are already used safely in other conditions. We hope the final decision on the first drugs to be tested will be announced in the summer, with the trial opening to the first participants later this year.

Our ambition

Jeremy says, "Octopus will adapt to test the very best emerging medications in progressive MS and ultimately lead to treatments for progression becoming available much sooner. This is a huge step-change compared to previous research and it is extraordinarily exciting!"

Dr Emma Gray, our Assistant Director of Research, says: "There's still nothing widely available for everyone with progressive MS that could slow or stop progression. Octopus is a key part of our ambition to stop MS and by 2025 we hope to be in the final stages of testing treatments for everyone with the condition."

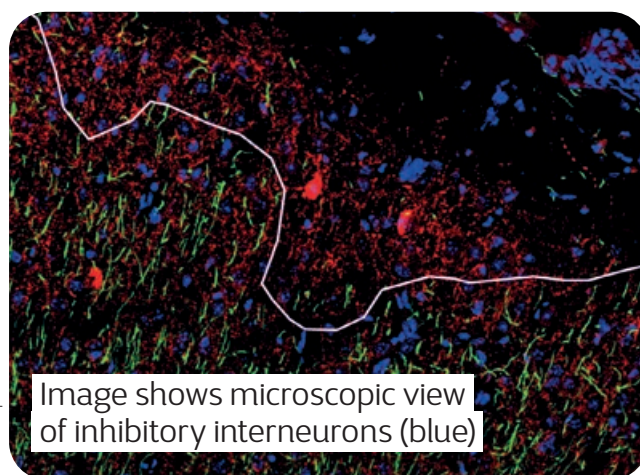
Look out for more news about Octopus on our website over the coming months.

Understanding how different types of nerves are affected by MS

Current MS treatments target the immune system, but to truly stop MS, we need treatments that protect nerves from damage. There are many different types of nerves in the brain, so we need to know which ones are most affected by MS in order to protect them.

Using brain tissue samples from the MS Society Tissue Bank, researchers found a reduction in the number of a particular type of nerve cell called "inhibitory interneurons" in tissue from people who'd been living with MS compared to those without MS. Another type of nerve - stimulating neurons - remained the same. So it's clear not all nerves are damaged in the same way by MS.

The researchers found the same pattern in mice with an MS-like condition, so they can now use these mice to look for treatments that can protect inhibitory interneurons from damage in MS.



Lida Zoupi

Image shows microscopic view of inhibitory interneurons (blue)

read

Read more about the latest MS research news on our website: mssociety.org.uk/latest-research

New MRI techniques detect changes in early MS

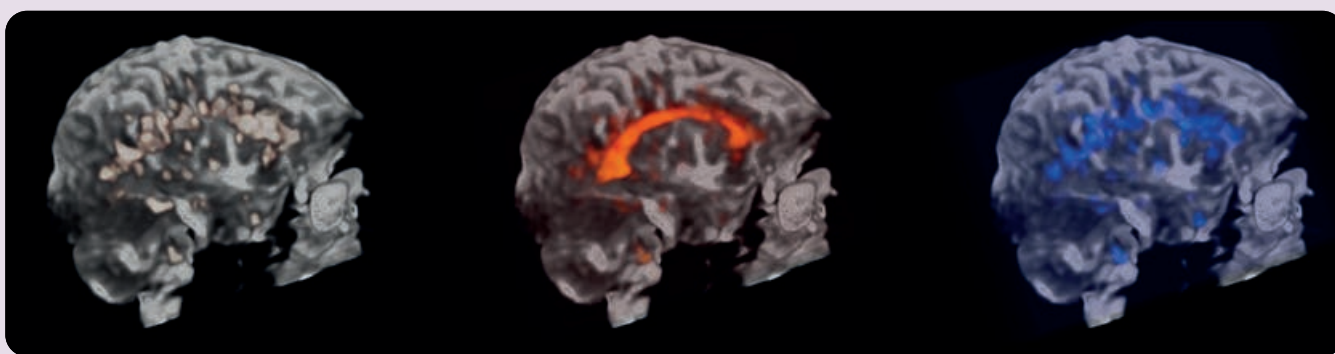
MRI scans are routinely used to diagnose and monitor MS but these scans don't pick up everything happening in the brains of people with MS. We know other changes take place because we see evidence in brain tissue donated

by people with MS after their death.

Now researchers have found new MRI techniques can detect some of these changes even in people only recently diagnosed with MS. They could even see a link between the presence of these changes

and subtle signs of clinical disability, like slower walking.

The next step is to see whether these changes relate to how someone's MS develops over time. If they do, we could eventually use the information to give people more certainty about their future.



Left image shows conventional MRI scan; centre and right images show two new techniques – known as NODDI and Sodium MRI

Sara Collorone

New insight on vitamin D and MS

Low vitamin D levels seem to play a role in your risk of developing MS. But we don't know whether vitamin D supplements could treat MS. The first step is to find out whether vitamin D levels are actually different in people with MS compared with the general population.

A recent study collected information from 388 people with MS about their vitamin D levels. Each participant also recruited a friend without MS.

Using the UK MS Register, participants filled in surveys about their use of supplements,

time spent outdoors and diet. They also received kits to collect their own blood samples.

The team discovered people with MS had higher levels of vitamin D in their blood. The main cause of this difference was that more people with MS (almost three-quarters) took vitamin D supplements than people without MS (only one-quarter).

This study gives us valuable insight into the vitamin D levels of the UK MS community, which will be vital for informing the design of future studies.



plus Turn to page 38 to read about our new Centres of Excellence awards

istock



Over to you

Your questions answered

We don't yet know for sure why people get MS. It's likely to be due to a mix of genes, something in your environment and some lifestyle factors. We answer some of your questions on the risk factors associated with developing MS.

Q I was diagnosed at 14, so how can it have been caused by lifestyle factors when my life had only really just begun?

– Anna

Research suggests the risk factors for developing MS in your childhood are similar to

the risk factors for developing it as an adult. These include:

- being significantly overweight
- having low vitamin D levels in your blood
- being exposed to smoking
- catching the EBV virus (which can cause glandular fever)
- your genetics

But none of these cause MS on their own. Finding similar risk factors for adult and childhood MS gives us confidence that they really are part of the reason MS develops. Unfortunately though, we don't yet know why MS sometimes develops earlier in life.

Q When I was young, we emigrated from a hot place to the UK, so I suspect vitamin D played a role in my MS? – Wai Sum

The risk of developing MS isn't the same in every country. Several studies show people who've moved to a new country during childhood adopt the risk of the country they move to. But if people migrate later in life (in their twenties or later) they keep the risk of their country of birth.

A study from Sweden in 2015 also found a link between teenagers with MS and low exposure to summer sun in their teenage years. These studies form part of the evidence suggesting environmental factors during childhood may play a role in why people later get MS. These include having low levels of vitamin D, most likely caused by not spending enough time in the sun.

You can find out more about vitamin D research at mssociety.org.uk/vitamin-D

Q Could anything that happened when my mum was pregnant with me have increased my risk of developing MS? – Lin

Researchers are exploring the role of a mother's lifestyle or environment during pregnancy, and the likelihood of her child going on to develop MS later in life. For example, in Finland, a study has been following a group of mothers since 1983, and they've seen an association between insufficient vitamin

D in the mother's blood during pregnancy and a later increased risk of MS in her child.

But it's not easy to tell whether the increased MS risk is actually a direct effect of low vitamin D on the baby in the womb. Insufficient vitamin D in the mother's blood is likely to be caused by not spending enough time in the sun. So this might simply be an indication of what the child's lifestyle might be like in later life.

ask

Get the right information

Our research staff are not medical professionals. This page is designed to provide general information. If you have specific health questions please talk to your healthcare professional.

If you'd like to talk in confidence about any aspect of living with MS, you can call our MS Helpline free on **0808 800 8000**, or email helpline@mssociety.org.uk

Q Can I reduce my risk of MS? – Catherine

Most people's risk of MS is very small. Even if you have an identical twin with MS, the chance of developing it yourself is 1 in 5. MS is caused by a mix of factors, so we can't yet pinpoint one thing you could do to eliminate your risk of developing MS. But if you're worried, we do know some things, like not smoking, can reduce your risk. Find out more at mssociety.org.uk/causes-of-ms

Risk over your lifetime of getting MS if you...

Have a parent with MS



1 in 67

Have a brother or sister with MS



1 in 37

Have an identical twin with MS



1 in 5

Is MS written in our genes?

Mel Webb, who lives with MS, talks to **Dr Calliope Dendrou**, genetics researcher at the University of Oxford, to find out what we know about MS and genetics.

Getting an MS diagnosis often leads people to take to books, magazines and the internet to try to understand how they can best manage life with this complicated condition.

I started my research from hospital and was met by a raft of information. But I found it hard to find an answer to the question; why me? This led me to the fascinating world of genetics.

What are genes?

Genes are instructions for our bodies. They're passed on from our parents and influence things like hair and eye colour. They also affect our chance of developing certain health conditions, including MS.

We know that over 200 genes are linked to MS and researchers like Calliope are trying to understand if they have anything in common.

Calliope says, "So far most of the genes linked to MS only



Mel Webb

have a small individual effect on the risk of developing MS. It's likely that different combinations of these genes affect our chance of getting MS. So far, most of the genes we've found are involved in the immune system. This makes sense given that in MS the immune system (which normally fights off infections) mistakenly attacks the protective coat around our nerves."

Is MS my biological destiny?

My diagnosis took a long time. So many tests, scans, and questions about my family history. This made me curious about whether our likelihood of developing MS is determined by family genetics. And could we one day predict if and when people might develop MS?

Calliope explains, "Most people





“Most of the genes linked to MS only have a small individual effect on the risk of developing MS.”

Dr Calliope Dendrou

who have a relative with MS won't have it themselves. But your chance of developing MS can increase if you have a relative with the condition. If you have an identical twin with MS you have a one in five chance of getting MS. So that tells us our environment plays a role too.”

So while trends in families are important, more research is needed.

Looking for patterns

Although there's no one else in my family with MS, there are lots of occurrences of other immune system conditions (asthma, lupus, psoriasis, eczema, sarcoidosis and arthritis to name a few). I asked Calliope to shed some light on why. Could genes be involved?

She explains, “Some genes are common to a number of

conditions because they play a general role in switching on the immune system. I work on a gene called TYK2, which is involved in many different immune system conditions. But some genes are unique to specific immune disorders.”

What's next?

Calliope says, “If we can understand more about how genes link to other risk factors, we may be able to find ways to control our overall risk of MS.”

It's an exciting time for MS genetic research, which is also exciting for those of us living with MS. If we knew which genes to watch in terms of who is more likely to get MS, in the future we could design ways to reduce that risk. Perhaps then, the destinies of people with MS would be brighter than we can imagine.



Which genes are involved in MS?

HLA genes are a group of genes that provide instructions for molecules that help the immune system distinguish invaders from the body's own cells. They were some of the first to be linked to MS. Some HLA genes make people more likely to develop MS, but some may decrease the risk.

TYK2 is a gene involved in relaying signals between different immune cells and triggering them to become active. Different versions of the gene can affect someone's chance of getting MS.

These are just two examples of more than 200 genes linked to MS.

Could a virus trigger MS?

Research Network member **Sarah Robinson** asks **Dr Cassandra Munger** from the Harvard School of Public Health whether the virus behind glandular fever could play a role in the development of MS.



Sarah Robinson

Viruses have been prominent this year as we all try to live with COVID-19. But when I was diagnosed with MS, I didn't know a virus could be partly to blame.

One virus – the Epstein-Barr Virus (EBV) – triggered the interest of Dr Cassandra Munger 20 years ago. Cassandra's relationship with MS began when her mother was diagnosed with the condition. This sparked her passion for studying MS.

EBV and MS

"Unlike other viruses we may encounter, EBV stays in our bodies for life," says Cassandra. You can see evidence of an earlier EBV infection by looking for antibodies. Antibodies are created by our bodies' immune cells to fight viruses and other invaders.

By measuring the levels of EBV antibodies in someone's blood, Cassandra can see if they've ever been infected with EBV and how strong their

body's immune response was.

Lots of different research studies have found associations between EBV antibodies and MS. People without EBV antibodies almost never have MS. And people with higher levels of these antibodies are more likely to have MS than people with lower levels.

A study of the US military

"Because researchers are seeing the same patterns everywhere we look", Cassandra says, "we think EBV must actually be one of the factors that can play a role in triggering MS."

But to be sure, we also need to know the infection occurred before MS developed. So



Dr Cassandra Munger

What is EBV?

- EBV is a very common virus – by adulthood around 96% of people have been infected.
- Most people get infected with EBV in early childhood, usually passed through saliva.
- Most people aren't aware they've been infected with EBV but some experience symptoms as glandular fever (sometimes called mononucleosis).

"The risk of MS increases around 27-fold after EBV infection. The pattern is very striking."

Dr Cassandra Munger



Kassandra's been analysing EBV antibody levels in blood samples taken from the US military over a long period of time.

Some people who were originally EBV-negative (they hadn't yet been infected with EBV) later became infected with EBV. These people had a much higher risk of MS than people who remained negative. "The risk of MS increases around 27-fold after EBV infection," she says. "The pattern is very striking."

But most studies on EBV and MS have involved white

populations. So she now plans to study a broader group to understand whether the effects are true for everyone.

Could we prevent MS by preventing EBV infection?

Kassandra told me: "It's proving very difficult to develop a vaccine for EBV." So currently, scientists are focusing on a vaccine to prevent people who become infected with EBV experiencing it as glandular fever. But she cautions: "Even if this was successful, the impact on MS is not completely clear, because many people with MS

didn't have any symptoms of glandular fever even though they had been infected with EBV."

She also tells me, "We know EBV on its own isn't enough to cause MS." What happens to a person on top of that matters too. So we need to know how EBV interacts with other risk factors like vitamin D and your genetics."

There's more work to do, but great scientists like Kassandra have devoted their whole careers to figuring out "What causes MS?" One day I believe we'll be able to stop anyone from developing it.

A new phase of myelin repair research

We've committed to raise £3.7 million to support the next phase of research at our Centres of Excellence in Cambridge and Edinburgh. **Dr Thora Karadottir**, co-lead of the Cambridge Centre, tells us about their plans for the next five years.



Dr Thora Karadottir



The MS Society Cambridge Centre for Myelin Repair is all about bringing together researchers with a shared vision. We all want to achieve the same ultimate goal – a world where there are no consequences of an MS diagnosis.

And we all believe discovering ways to boost the body's natural ability to repair myelin – the protective covering around nerves, which is damaged in MS – is key. Although we come at it from different perspectives, working together massively enhances the work we could do individually.

I'm interested in how brain cells communicate with each other. But to understand MS, we need to know how they communicate with immune cells too. For that, I need an immunologist. At the Centre, there's always the right expert to hand.

One big happy family (no, really!)

One exciting thing about this phase is our focus on training the next generation of myelin repair experts.

Students will be co-supervised by researchers from different areas of myelin repair research, so they'll

be perfectly placed to see patterns we might otherwise miss. And our partnership with the Edinburgh Centre for MS Research will give them access to an even broader community of MS experts.

They'll get first-hand experience of how collaboration allows you to do more exciting, fruitful work and can take that lesson into their future careers.

Ageing

One of our key ambitions is to understand how myelin repair interacts with ageing. MS affects people of all ages, but it doesn't happen exactly the same way for a



six-year-old, a 16-year-old and a 60-year-old.

I'm a lab scientist looking at how nerves notify other cells in the brain that their myelin has been damaged. Like a ship that's hit an iceberg – the captain needs to send out a distress call to get rescued.

We've discovered this communication changes as we age. For instance, there's a period of time when those other cells don't want to listen to the distress call. We need to find out what drives these differences, so we can help rescuer cells at all ages behave like the happy, communicative cells of young adulthood.

Cutting-edge brain imaging

What's beautiful about the Centre is that each piece of research feeds into the next like a production line.

So some of my colleagues use my findings to run small trials testing drugs that may help nerve cells communicate more effectively.

Another group are working on how we could use MRI to measure myelin repair as standard in MS clinics. We've started doing this in some clinical trials but if it became routine, we'd get so much valuable data on how myelin repair changes as you age.

Not only could we exploit that information to develop new treatments, but neurologists could say to someone, "Good news, your brain is repairing better than it was a year ago." Having a method to follow how someone's MS is progressing in the brain means we could help people make fully-informed decisions about treatments.

A bright future

When I was born in the 1970s, an MS diagnosis was utterly different to one today. Few neurological conditions have seen anything like the progress in disease modifying therapies we've had in MS.

Cambridge researchers made a huge contribution to that change – like my co-lead, Professor Alasdair Coles, who was instrumental in developing alemtuzumab (Lemtrada), a highly effective treatment for relapsing MS.

I'm incredibly honoured to now be working with them to bring about the next revolution in MS – treatments that will stop MS getting worse.



Co-lead Professor
Alasdair Coles

A global effort to stop MS

Our new Head of Research **Dr Clare Walton** joined the MS Society from the MS International Foundation. She tells us why she believes a global effort is key to stopping MS.



Dr Clare Walton

If the coronavirus pandemic has taught us anything, it's the tremendous value of scientists around the world working together towards a common goal.

In a matter of months, the global research community made incredible progress in understanding the science of the new virus. Now, thanks to that collaboration, we have effective treatments and vaccines, and hopefully a path back to normal life.

COVID-19 and MS

Collaboration has been vital too for understanding the effect of COVID-19 in people with



Read about COVID-19 and DMTs at mssociety.org.uk/covid-and-dmts

MS taking different disease modifying therapies. In my former role I led a project to bring together information on 10,000 people with MS from across 80 countries. The team from the MS Society-funded UK MS Register took part and our findings informed the guidance for people with MS from neurologists around the world including the Association of British Neurologists.

A single, shared vision

But it's not just about COVID-19. MS researchers are working internationally to better understand MS and discover ways to stop it. By combining

our resources and sharing knowledge, we can make progress faster.

At least 2.8 million people worldwide are living with MS. And every day in my former role I'd talk to neurologists, researchers and patient organisations from all continents who are united in their ambition to one day stop MS.

Although over recent decades we've made great progress in preventing relapses, there are very few treatment options for progressive MS. To speed up treatment development, the MS Society co-funds the International Progressive MS Alliance which brings together



Canada and the US to find drugs that can protect nerve cells in MS.

We hope promising drugs identified in their labs will eventually go on to be tested in clinical trials, such as Octopus, our new trials platform for progressive MS, which you can read more about on **page 28**.

Coming together

Despite the challenges of the last year, I've been thoroughly inspired by how the global MS community has come together. Progress in medical research can often feel too slow. But I'm confident that through international collaboration we will find a way to stop MS sooner.



Find out more about the Alliance at mssociety.org.uk/alliance

MS organisations, industry partners and individuals, specifically to achieve this goal.

New treatments to protect nerves

The Alliance awards funding to help researchers with unique expertise and resources in different areas of the world work together to make crucial breakthroughs.

Like the BRAVEinMS Network which brings together teams in Italy, France, Germany, Europe,

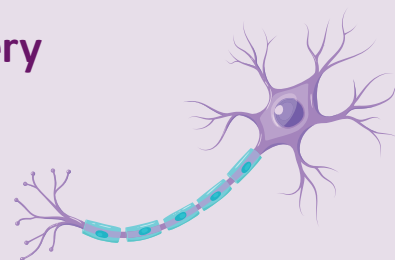
A collaborative discovery

Our nerves are surrounded by a substance called myelin that keeps messages flowing smoothly and protects nerves from damage. But myelin itself gets damaged in MS.

The BRAVEinMS team recently studied a specific type of cell crucial to repairing damaged myelin.

New myelin is created when special stem cells turn into myelin-making cells, so the researchers wanted to know if those stem cells work properly in MS. They found that stem cells taken from people with MS still have the potential to repair myelin in mice.

Although still at an early stage, this provides a valuable insight into what elements of the myelin repair process we need to target if we want to find treatments that can boost myelin repair.



Tips for managing MS and sex

Whether you're single or in a relationship, MS might have changed the way you approach sex and intimate relationships.

It's not always about the physical things and it's not always down to the MS. But getting help to manage symptoms like fatigue or pain could make a difference. And if treatment side effects cause problems, you and your MS team could discuss other options.

Whatever the reasons, if you're finding it difficult to get that spark, there are things you – and partners – could try.

Communicate – understand how MS is affecting both of you. Try to avoid criticising or blaming. Sentences that start with “I feel...” and “I would like...” can work better than “You

don't...”. You could write down how you feel.

Discover what works for you – by exploring your own body through masturbation and with body mapping (where you gently touch all parts of the body to identify what results in sensual pleasure, discomfort or sensory change).

Don't forget about feeling sexy – that's not just about physical appearance, but it can be a boost to spend time on your hairstyle/makeup/waxed moustache (delete as appropriate).

Inform yourself – forget the myths around sexuality, sexual difficulties and

disability. Learning about how MS symptoms can affect relationships and sexual function makes it easier to understand and discuss how you feel.

Create a sense of intimacy and physical closeness – this could be holding hands or hugging. It could be a massage. This kind of intimacy might be particularly important in a relationship if penetrative sex is no longer possible.

learn

Visit mssociety.org.uk/sex-and-relationships

or join our webinar on 12 May with counsellor and sex and relationship therapist Nikki Orr. You can sign up at mssociety.org.uk/webinar-relationships



My husband, my partner... my carer?

Rose asked her husband if he considered himself to be her carer. Here's an extract of their conversation on our blog.

Me: After I told you I had MS, what were your initial thoughts?

Paul: Well, I didn't have that much previous knowledge of MS, not in-depth, anyways. My initial thought wasn't that I felt put off but that I should learn more about it. It certainly didn't make me not want to be with you, and I didn't see it as a problem. At the end of the day, I was dating you, not your illness. I never thought about mixing the two.

Me: Did the fact I have MS scare you?

Paul: I don't think "scared" was how I felt. I had to think more in terms about

the future. I had to consider if I saw a future with you, MS aside. Because I knew it wasn't the type of situation, after you had told me, where we could keep things casual if we wanted to continue being together. And, well, YES I wanted to be with you, so that was kind of it.

Me: Did it make you any less attracted to me?

Paul: Absolutely not.

Rose's blog struck a chord with you on Facebook.

Alice

It's very brave of you to talk about this issue, thank you.

Elizabeth

At first when my partner was diagnosed, I felt a lot of anger about it and loneliness. Eventually you start to accept the situation and work together on issues that come up.

Angela

I love your positivity on this subject. I still feel terrified about what my MS future holds. So, for now, a day at a time is all I can do.

Read our information on family and relationships at mssociety.org.uk/relationships



Are you a budding blogger?

If you'd like to write for our blog, get in touch with us at msmatters@mssociety.org.uk

Do you have a comment on something you've read in MS Matters or on our website? Let us know!

✉ Email msmatters@mssociety.org.uk

f Facebook fb.com/MSSociety

t Twitter [@mssocietyuk](https://twitter.com/mssocietyuk)



Your top tips on tech that helps you every day

Technology can be a great help when you're living with MS. We asked you for your top technology tips. From smart speakers to apps and social media, here's what you told us.



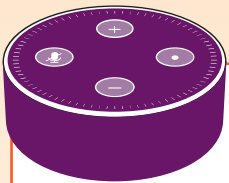
I'm a member of a Facebook group called muMS which is a support group for mums, mums-to-be and those trying to become a mum, all who have a diagnosis of MS or are undergoing tests for it. It's been a massive help to me for many years.

Manisha



I wouldn't be without my smart speaker for playing music and setting alarms for getting ready for my son's school run. I've linked it to my doorbell camera too, so I can see then speak to those at the door from the comfort of my armchair. This helps save my energy.

Joanne



I've got a few Alexa Dots scattered around the property. Excellent for putting the lights on/off, heating on/off, checking the front door camera. Also, if I were to fall and I couldn't get up I could ask Alexa to ring one of my contacts for help. Between Alexa, my partner and my son it's working at the moment.

Russ

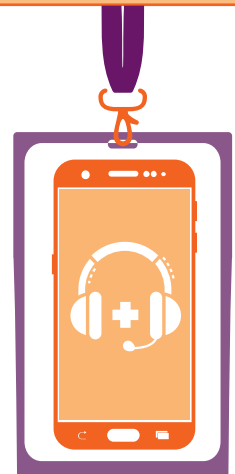


Talk-to-text typing and voice notes. They save me on high fatigue days and when tremors and pain are out of control. Using these eases my pain and keeps me connected.

Roxanne

Keep your mobile phone in a lanyard case with a rope attached so you can hang it crossbody, or around the neck, at all times (except perhaps in bed!). Then you're never grappling in your bag or pocket to take calls, able to always keep in touch and prepared for emergencies. It keeps your phone protected and in tip-top condition too!

Jacqueline

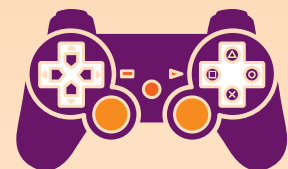


I can access my GP through an app called Patient Access. You create an online account, which allows you to book a GP appointment, order your repeat prescriptions and review test results.

Theresa

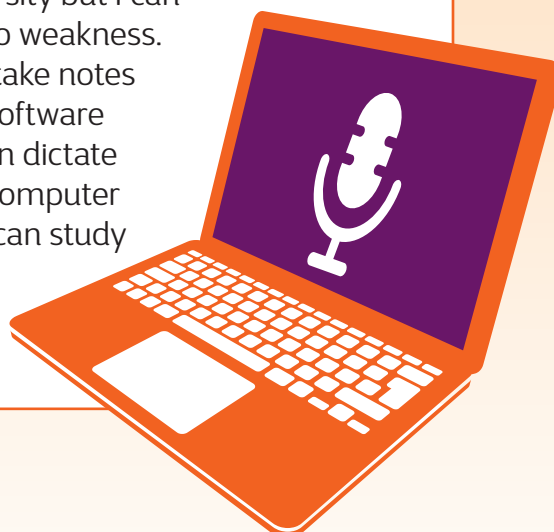
I've managed to stay in touch with friends through PlayStation Network.

Colin



I'm studying at university but I can no longer write due to weakness. I wouldn't be able to take notes without the Dragon software on my computer. I can dictate notes or control my computer using the software. I can study independently now using my voice.

Karine



Thank you to all who shared their thoughts.

In the next issue, we'd like to ask you: How have people supported you, and how have you supported others, during lockdown? Email [mismatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk) or keep an eye on our Facebook page, [facebook.com/mssociety](https://www.facebook.com/mssociety)

Five tips for managing claustrophobia in an MRI machine

Living with relapsing MS, I've got used to regular MRI (magnetic resonance imaging) scans to check for disease activity, writes blogger **Jessie Ace**.



The scans can make me feel claustrophobic. Here are my top tips that have helped make my scans easier.

1 Breathing techniques. Focusing on my breathing is a great distraction, and it also helps keep me calm. It encourages my brain to block out the logical, over-analytical part and lessens my anxiety. There are lots of tips on breathing exercises online.

2 Fluids. Having a sip of water helps calm my anxiety before the scan. If you're having a scan using contrast dye, drinking plenty of fluids beforehand can help the nurse find the vein. (Contrast dye is injected before the scan to make it easier to understand the image on the scan.) More fluid may work for some more than others – you know your body better than anyone else.



3 Focus on a reward. I love having a reward after an MRI – it gives me something to focus on while in the scanner. I spend the time thinking about the pizza I'm buying on my way home. Maybe your ideal reward could be your favourite food, seeing your family after the appointment or watching your favourite TV show?

4 Keeping my eyes closed. This can help if you're claustrophobic like me. Closing my eyes from the start and keeping them closed till the end helps me forget where I am and focus on other things.



5 Find a distraction. A lot of people I know count the “bang” sounds the scanner makes during an MRI. I like to make songs out of them. Sometimes you'll have access to the radio and can hum to the music.

More information

Read more about having an MRI scan at mssociety.org.uk/MRI. What are your tips for having a scan? Let us know at msmatters@mssociety.org.uk

When the carer needs to go into hospital

Our anonymous columnist, a full-time carer for his wife who has secondary progressive MS, writes about planning for emergencies.

Recently I underwent a scheduled procedure in the day-surgery unit of our local hospital. I was in and out in a matter of hours. Because we had prior warning, we were able to make arrangements to cover my absence. A close friend sat with my wife during the time I was away and saw to her needs, as well as having a great old chat!

The question arises, however, if the carer should suddenly be taken ill, needing hospitalisation. What then? Are there arrangements in place to cover this situation, and are there arrangements to cover any long-term absences?

After all, the dynamics of a smooth functioning domestic situation depend on the good health of the carer!

Emergency cover

First and foremost, ensure you have easily accessible contact numbers for your GP, MS nurse and social care team. It's a good idea for anyone who gives any level of care and support to have a care plan in place. This should cover all eventualities, including emergency

cover. As time marches on and needs change, so should the plan.

This plan will have in place all the services which are required. These may range from a full-care package, with teams attending at various times in the day, to a "hands-off" approach with the carer and the professionals happy to keep an eye on things. The level of input depends on how much the carer is capable of managing.

Care packages should include, where necessary, the input of other health professionals: physiotherapists, podiatrists, chiropodists. Within our carers' group, we've found the occupational therapist to be the professional who can solve a problem on the ground. Our mantra is: "make the occupational therapist your new best friend!"



Within our own carers' group, some have needed the service to be boosted, an increase in care-provision and input at times of crises.

Impacts of COVID-19

In a perfect world and assuming the various agencies talk to each other, there should be a seamless transition from one level of care to another with no interruption to service.

However, under the current restrictions, we have heard of care provision being reduced on occasions and folks not receiving the level of input that they routinely have come to expect.

This is understandable of course, as social care managers juggle with staff absences, trying to maintain a service acceptable to both provider and client. Under extremely trying circumstances, all our care providers are facing the most daunting of conditions.

Helpful hints

- **Register with your local carers' centre.** They should be able to offer practical support and advice.
- **Consider installing a home-alarm which links to your local care services.** This enables an immediate connection to a response team which should be able to make any instant decisions.
- **Carry with you a note of contact numbers "in case of emergencies" (ICE).** An ICE note is vital should an accident happen to you while you are out. First responders will then be able to make any necessary calls.
- **Make sure you're registered as a carer with your GP** (on your records and those of the person you care for) to receive updates about services that might be able to help.

EMERGENCY PLANS



More information

Find out more about support for carers at mssociety.org.uk/carers-support, while Carers UK has useful information about care plans at carersuk.org/planning-for-emergencies. We're campaigning to improve social care and support for people with MS. Find out more at mssociety.org.uk/care-campaigning

Getting to know you...

Sandra Dodds joined us this January as a volunteer Group Coordinator for the East London MS Group.

Why did you get involved with the MS Society?

I've been in the social care field for 10 years and worked with people from all walks of life.

When this role with the MS Society came up, I went for it. I'm passionate about supporting others to be their best and using my previous experiences as a trainee manager, support worker and volunteer.

What did you want to be when you were growing up?

I didn't know exactly what I wanted to be, but I knew I wanted to help people and change their lives for the better. I'm still working towards this goal – by using my knowledge in social work and giving my time to support others.

What or who is the love of your life?

My son. I love everything about

him! His intelligence, his ability to make me laugh, his polite and caring nature.

When were you happiest?

Right now. I was always looking to the future before, but now, I just want to appreciate what I have in this moment. With the pandemic, this has hit home even more.

Where's your favourite place you've travelled?

Japan, when I was in my early 20s. I remember it as a spiritual, beautiful, friendly and interesting country, so full of contrasts – very advanced in technology yet still quite rooted in traditions. I loved their super-fast trains – it was easy

to get around even though I didn't speak any Japanese!

If you could have a superpower what would it be?

What comes to my mind is having the ability to be positive always, so I can also encourage others to be positive and to believe in themselves. And to have a positive mindset is helpful in any given situation!

What is the most important lesson life has taught you?

Believe in yourself and everything else comes after that. If you believe in yourself, you'll love yourself and you'll also love others.



We're developing something that's just **For you...**

We want everyone who is affected by MS to feel supported, connected and informed.

That's why we've been working with our MS community to develop **For you**, a new online experience that will:

- give you access to expert information tailored to your needs and interests
- show you where you can access services and support locally and nationally

- connect you with other people who, like you, are affected by MS
- keep you up to date with the latest research and developments in our fight to stop MS.

How it works

It's really easy. Create a free online account and control what you see – news, tips, stories, latest research, ways to manage MS – the choice is yours.

To find out more including when we'll be launching For you, visit mssociety.org.uk/new-for-you



Volunteer spotlight: Jacky Davies

Volunteer, Bridgend MS Society Group



Before COVID-19, we'd meet each week for physio, lunch, yoga and a chat. We had monthly coffee mornings and curry nights and I'd arrange a bus to pick everyone up.

I've only been out of the house three times since last March. I don't have to shield but I'm vulnerable when I'm out as I can't get out of the way of someone quickly. I live on my own. My daughter and a local volunteer, Nick, shop for me. I've always been independent and giving the reins to somebody else has been difficult. But I've had to get used to it.

Things are so different now, but we make sure that we stay connected even if it's just phoning someone.

It's been a difficult year for

our community in Bridgend. We lost our dear friends Tim, Bob, Chris, Maureen, John and Elaine. We couldn't mark their passing the way we wanted but they will be forever in our hearts.

Our group is working

Weekly planner

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Coffee morning	Physio	Tai chi	Quiz	Physio	Knit & Natter	
Yoga	Young at Heart Group	Mindfulness	Time Chat	The Zoom Inn pub	Choir	
Bingo						

EAT REST SLEEP

as a team to support each other. We set up a Zoom account to keep meeting. I can't organise a bus anymore, but I encourage everyone to join us on Zoom instead!

Being online has meant that I have taken part in activities I wouldn't normally do. Thanks to MS Cymru, I'm now doing tai chi, physio, yoga, coffee mornings, bingo, quizzes, knitting and crafts, choir and Time to Chat. I'm so busy now I wonder, what did I do with my time before?

I'm meeting with people living with MS from around Wales and the rest of the UK who I wouldn't have met ordinarily. It's wonderful making new friends.



talk

Need support and information?

Our MS Helpline can offer emotional support in difficult times. Call **0808 800 8000** or email helpline@mssociety.org.uk

Fantastic fundraisers

From award-winning quizzes to inspirational aquatic challenges, the next four pages are dedicated to your fundraising efforts. Thank you for your incredible support!

Our pub quiz wins innovation award

We're delighted to announce that our virtual quiz, Pub Quiz Live! has won an ideasUK Innovation Through Crisis Award for 2020.

More than 25,000 quizzers took part in eight quizzes broadcast across the year, raising £62,000. Our Ambassador BBC Radio 1 DJ Scott Mills hosted the quizzes on our Facebook and YouTube channels.

The annual ideasUK competition celebrates the most inventive ideas created by organisations across the world. The Innovation Through Crisis Award was a new category introduced in 2020 to recognise an idea that responded to the extraordinary circumstances of the coronavirus pandemic.

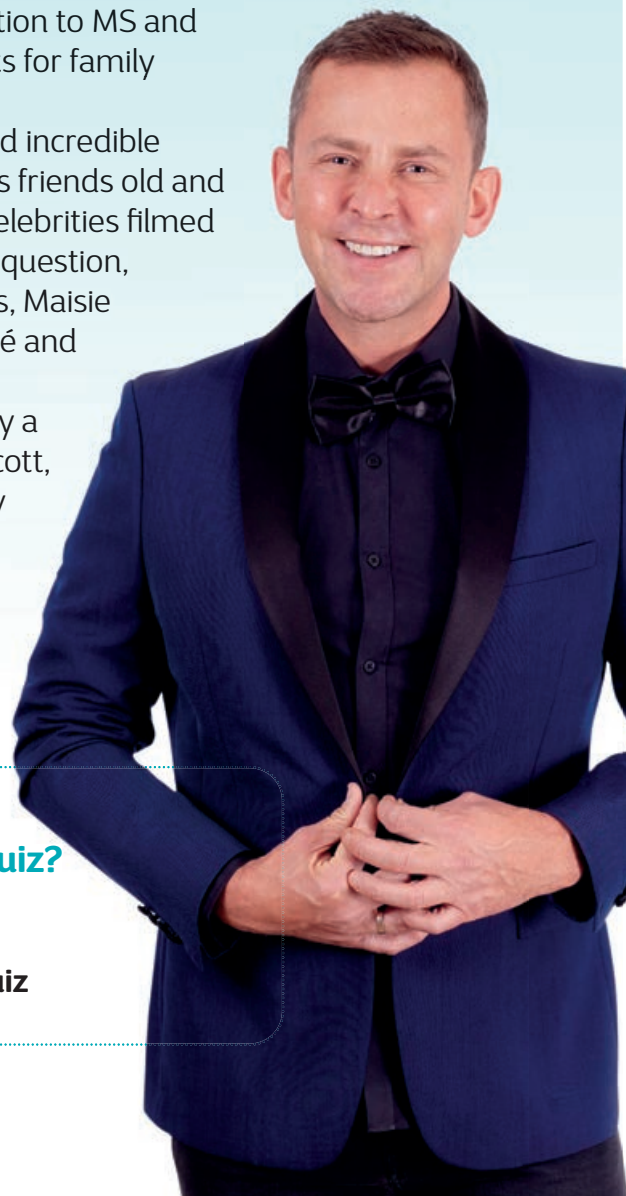
Inspired by the popularity of virtual pub quizzes during the first lockdown, Pub Quiz Live! was commended for being both an innovative way to raise funds and a platform that connected the MS community at a difficult time.

Scott hosted six weekly quizzes in March and

April and two more in the run up to Christmas. Quizzers could use a live chat function to connect with Scott and each other, with many sharing their connection to MS and requesting shout outs for family and friends.

The quizzes enjoyed incredible support from famous friends old and new. More than 30 celebrities filmed themselves asking a question, including Andy Serkis, Maisie Williams, Emeli Sandé and Alan Carr.

We would like to say a huge thank you to Scott, his amazing celebrity guests and all the quizzers who made Pub Quiz Live! an award-winning success.



join

Inspired to host your own virtual quiz?

Sign up to receive our free downloadable pack at mssociety.org.uk/your-diy-quiz

A feel-good labour of love

Motorcycles have always been a big part of John and Florence Martin's lives. They first bonded over their love of bikes and made many amazing journeys together.

Sadly, Florence gave up riding after an accident in 2013, and a diagnosis of primary progressive MS several years later. Now she rides pillion with her husband and recently started riding a moped.

John, who restores classic motorcycles as a hobby, decided to take apart and

rebuild a 1980s Suzuki Katana and raffle it to raise money for us. He contacted his motorcycle pals with his brilliant idea.

Florence says: "Many generous offers of help came from family and friends, the motorcycle community and businesses such as Suzuki.

"People donated their specialist skills and sent us parts from as far as Australia. It's been an incredible, feel-good project from day one!"

Find out more about the raffle: mssoc.uk/bike-raffle



Around-the-world pilot comes down to earth for MS research

Donkathon is the latest idea from one of the world's top female pilots Polly Vacher. Polly plans to take her two donkeys, Wizard and Muffin, on a 200-mile fundraising adventure from Oxfordshire to North Wales, starting on 25 June.

Polly has flown solo twice around the world in a single-engine aircraft, raising over £500,000 for the charity Flying Scholarships for Disabled People.

After unsuccessful eye surgery, Polly is no longer able to fly. She came up with the idea for Donkathon while recovering in hospital. The journey is expected to take four to five weeks, covering up to 10 miles on travelling days.

Polly says: "My nephew has MS, which is why I want to raise money for research as



part of the Stop MS Appeal. I'd love people to get involved with the journey, particularly those with MS who may wish to meet up or ride along for a day."

Find out more at donkathon.org
Please check the latest government guidance on COVID-19 before joining events.

1 man, 1 boat, 51 days and 3,000 miles for MS

We regularly report on our incredible MS Superstars who go the extra mile for us but there's one who has just gone 3,000 miles!

Gareth Reynolds from Pembrokeshire set off in early December on one of the world's most gruelling challenges to row solo across the Atlantic Ocean to raise vital funds for us. He is aiming to raise £100,000 for our Stop MS Appeal, to find treatments for everyone with MS.

Gareth says: "MS is a cause really close to my heart. I have close family members and friends who have the condition. The more I learned the more I realised that it is quite a common condition that can absolutely devastate lives."

When Gareth set off, he estimated that it would take him around 60 days, but he smashed this by

finishing on day 51.

During one of the world's toughest challenges, during which he rowed for up to 20 hours a day alone, Gareth navigated treacherous seas with 30 to 40-foot waves and faced storms and extreme temperatures. As if this wasn't enough, being attacked by flying fish brought a whole new challenge!



"I've been truly humbled by this whole experience and the incredible generosity people have shown throughout."

Gareth says: "I've been truly humbled by this whole experience and the incredible generosity people have shown throughout. It was a solo row but by no means a solo effort. Huge thanks to everyone who has supported me and donated."

More people have scaled Mount Everest or travelled into space than rowed across the Atlantic solo. Diolch yn fawr (thank you very much) to our Atlantic Dragon. You have done the MS community proud!

Bob's 100-swim challenge

Bob Coyne, who lives near Bognor Regis, loved swimming, windsurfing and kayaking in the sea. But in recent years, he had to give them up as peripheral neuropathy diminished the use of his legs.

Going to Pilates classes organised by his local MS Society group has helped. It also spurred him to challenge himself to complete 100 swims in the sea, over 100 days.

It wasn't easy. Bob used his walking sticks to get into and out of the water and often swam with friends to keep him safe. Six months on, he achieved his 100th

“The first time was nerve-wracking but now that I've got my confidence back, I hope to keep on swimming!”

swim and donated £230 to us as a gesture of his appreciation.

Bob, 75, says: “I didn't think I could swim anymore. The first time was nerve-wracking but now that I've got my confidence back, I hope to keep on swimming!”



Swimming success at windy Windermere

Tom Leeming has wonderful memories of childhood holidays in the Lake District. Last year, he signed up for the Windermere One Way challenge to swim the 11-mile length of England's biggest lake.

Tom says: “I always wanted to swim

Windermere, having been there many times – and to do it before turning 40 provided a great target. I also wanted to fundraise for MS research after seeing how my aunt died too young from this devastating illness.”

Tom is no stranger to open water swimming. He has swum both solo and in a relay team across the English Channel.

On the day of the challenge, poor weather stopped the formal event from going ahead. But instead of going home, Tom swam for almost seven hours in rough waters to reach the finish line and raise £6,600 for us.

He says: “It was exhilarating and exhausting! Everyone's generosity and support, and nine months of training, made it all possible.”



Walk, roll or stroll in 2021

Last year, you came out in force for My MS Walk and MS Walk Live to raise an incredible £160,000!

Whether you got involved at home, in the garden or around the block, the money you raised will fund life-changing MS research. We're so proud of how you came together during this difficult year.

In 2021, My MS Walk is back and bigger than ever! We need you to join our special virtual community and raise funds to help stop MS. So sign up and get walking, rolling or strolling in June.

You can log your miles and follow everyone's progress with leader boards and social media feeds on the My MS Walk hub. Look out for a special virtual event at the end of June to celebrate your achievements.

5 Piers Challenge

Julia Chard has been living with MS for over 30 years. To mark Julia's birthday in 2020, her husband David and daughters, Sarah and Catherine, signed up for the MS Walk in



Julia (centre) with her husband and daughters

Manchester. They didn't let the cancellation of that event stop them.

David says: "We hatched the idea to do a local walk along the Fylde Coast starting from St Anne's Pier to Fleetwood Pier also taking in the three Blackpool piers. It became the 5 Piers Challenge.

"We had a fabulous day out and were thrilled to raise over £1,500 for the cause which is so close to our hearts. We were so happy that despite her difficulties, Julia was able to join us for the final push to Fleetwood Pier."

join

Want to sign up?

Go to mymswalk.mssociety.org.uk

or contact mwalk@mssociety.org.uk

We're hoping to put on MS Walks in London, Bristol, Cardiff, Belfast and Edinburgh later this year. Visit our website for more details.



Dates for your diary

Ready for a challenge? Take part in one of our events and help us get closer to stopping MS. Visit mssociety.org.uk/fundraising-2021 for up-to-date information and to sign up. (Due to COVID-19, events may be subject to change.)

5 June

Zip it to Stop MS

Soar at speeds of over 100mph on the world's fastest zipwire in North Wales.

19 June

10 in 10

Conquer 10 peaks in 10 hours in the stunning Lake District.

17-18 July

Yorkshire Challenge

Walk, jog or run in the beautiful Yorkshire Dales with distances to suit all abilities.

24-25 July

South West Coast 2 Coast Challenge

New for 2021. Enjoy magnificent views as you walk, jog or run across Devon.

21 August

Ben Nevis Night Hike

Climb Scotland's iconic mountain by night on this unforgettable adventure.

Date of your choice

Skydiving

Take the leap at one of dozens of sites around the UK.

Spring Raffle

You could win £4,000

Enter today for your chance to win £4,000, another cash prize, or one of 20 M&S vouchers in our Spring Raffle.

It's a great way to help fund research into new treatments, and support for people with MS.



raffleentry.org.uk/mssociety
0330 002 0267

Closes Thursday 13 May

Yoga you can do in bed



Maxine Davis on how restorative yoga changed her life.

A couple of years ago, I was bedbound. I have lupus, fibromyalgia, Reynard's disease, nerve damage and tinnitus. Every day I was in pain – it felt like someone was plucking out my nerves. My mobility was very bad and I had constipation from the medication I was on.

When my doctor advised me to try yoga, I laughed! But I searched for “bed yoga” on YouTube and found something called restorative yoga. I started doing the postures in bed. My body loved it! I managed to go to the toilet, and I was in less pain.

Once I became more mobile, I used my sofa and then the floor. I started going to restorative yoga classes. After lots of



research, I decided to train as a professional yoga teacher.

My classes are designed for disabled people and those who have chronic pain, including people with MS. I always tell people they're in charge and that the main goal is to listen to what their bodies need.

I've built an online yoga class that people can do on their bed or sofa. During the pandemic, I've been giving free classes because I know what it's like to be in pain.

Search for “**Spoonie Yogi**” on YouTube or Facebook to find Maxine's classes.

Activity corner

Maxine's seated stretch

Ask someone to support you if you need it.

1. Sit on the edge of your bed.
2. Put three pillows on the bed to the right of your hips.
3. Stretch your hands and arms up to the sky.
4. Turn to the right and tighten your stomach muscles.
5. Lower your hands to the pillows on your right.
6. “Walk” your hands along the pillows, stretching gently until the top half of your body is lying on them.
7. Breathe deeply three times. Then feel the sensation of the pose for 10 minutes.
8. Peel yourself up off the pillows slowly.
9. Repeat on your left side.

Please read our disclaimer on page 5. Check with a health professional before starting a new kind of exercise or activity.

My close-knit online community

Diane Gist talks about how knitting has helped her make new friends.



Diane's lived with primary progressive MS for more than a decade and has been active in our local groups in Wales. But since lockdown her MS world has grown.

I've always made things, I'm of that era. I like doing things that are of practical use.

When we went into lockdown I joined the weekly online Knit and Natter group, run by the team in Wales. They sent everyone a pack of wool and I decided to make a pair of fingerless gloves. I used an old pattern of my mother's – priced at 4d! The first pair were really hard going. But once they were finished a girl from the group said, "What a fabulous colour!" and I posted them to her.

I've now made 55 pairs of gloves and have posted them to people all over the country. I learnt the pattern off by heart and I can make three pairs in a week – and watch TV at the same time. Knitting them

provides a good distraction from my legs as they can be twitchy and painful. It takes my mind off the pain.

These days there's not much structure in our lives, except Zooming. I wouldn't have done the gloves if it wasn't for Knit and Natter. Whatever

you're making, someone will like it and you can share the pleasure.

Don't worry what it looks like – just have a go. It also helps to do it with someone. Connect on Zoom or keep in touch to share your progress and encourage each other.

I'm looking forward to coming out of lockdown and being able to meet all the new friends I've made. It will be lovely to get together and share our crafts in person.

“Whatever you're making, someone will like it and you can share the pleasure.”

