Autumn 2024

your Advances

Your support, your impact

- Research updates
- Campaigning to get MS on the agenda
- Benefits Advice Service
- Highlights from 2024 so far

Welcome

It feels like this year has flown by and when I think about everything supporters like you have achieved, I feel immensely proud to be a part of such an incredible community.

Supporters like you do so much that it's impossible to fit everything into a 15-page newsletter. From our generous donors to inspirational fundraisers and incredible volunteers, I can't thank you all enough.

With your support, we're doing more to call on the new UK Government to take action, continue to fund groundbreaking research and provide services to support people affected by MS. With the number of people living with MS in the UK now estimated to be over 150,000 – 13% higher than we previously thought – our mission is now more important than ever.

Nick Moberly,
Chief Executive

In this issue

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mssociety.org.uk/advances
or by calling **0300 500 8084**
(Monday to Friday, 9am to 5pm)

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Multiple Sclerosis Society is a registered charity in England and Wales (1139257) and Scotland (SC041990), and a company limited by guarantee (07451571).
Carriage House, 8 City North Place, London N4 3FU

Research updates

So far in 2024, you've helped fund five new research projects. Read on to discover what's happening in the world of MS research thanks to your generous donations.

Training the next generation of MS symptom management researchers

This year with your support we launched two brand-new Doctoral Training Centres that will focus on finding effective ways to manage MS symptoms without drugs. In Glasgow, researchers will explore how physical activity can help people with moderate to severe MS, including traditional forms of exercise and newer approaches like virtual reality. And in London, researchers will develop new digital health interventions to treat MS symptoms.

Dr Clare Walton, our Head of Research, said:

"To achieve a world free from the effects of MS, we need to attract and develop the best talent in MS research. By providing funding and support for these PhD students, our Doctoral Training Centres aim to build capacity in MS symptom management research. All this will maximise the chances of their research making a difference to people living with MS."

In March we highlighted some of our recent Catalyst Award projects (innovative research studies which last 12 months) and asked for your help to fund more research like this. And you didn't disappoint! Supporters like you raised over **£105,000!**

Since then we've funded two new Catalyst Awards, read on to find out more.

Dr Emma Tallantyre

CATALYST PROJECT #1

Can blood markers be used to predict disability in progressive MS?

Blood markers are substances in the blood that can help understand what's happening in the body. It's thought that some blood markers may be able to detect nerve cell damage or inflammation.

Dr Emma Tallantyre and her team aim to identify a combination of blood markers that can predict worsening of symptoms in progressive MS.

How will it help people with MS?

The goal of this work is to develop a less invasive test that could accurately predict how MS will progress. This could then be used alongside, or potentially instead of, MRIs in early trials, speeding up the process of finding new therapies for progressive MS.

This work could also uncover a reliable single blood test to better predict future disability for people living with primary and secondary progressive MS. This could empower people to make decisions about their treatment and lifestyle.

If you want to know more visit **mssociety.org.uk/latest-research**

CATALYST PROJECT #2

Can doctors use artificial intelligence in MRI scans to help people with MS?

Doctors use MRI scans to identify areas of damage, or lesions, in the brain and spinal cord. But some subtle lesions may be missed by human error. And we don't yet know whether these subtle lesions can increase the chance of relapses and disability.

Dr Will Brown and his team will use artificial intelligence (AI) to identify these subtle lesions. And then look at whether people with these previously missed lesions had more relapses or more severe disability than people who didn't have any new lesions.

How will it help people with MS?

The results from this project will help the researchers decide whether the tool should be extended to wider use in the NHS. By understanding how subtle lesions can impact disability and relapses, the team could demonstrate the need for this tool and improve future care for people with MS.

Dr Will Brown

"We're so grateful to the MS Society for this award. If we find that this tool works, it could enable earlier detection of the condition worsening.

MRI data could be seamlessly added into electronic healthcare records to help early and efficient treatment. It would also markedly improve monitoring and prediction of the impact for people with MS."

Dr Will Brown

A spotlight on the Benefits Advice Service

More and more people were contacting us about their struggles to navigate the benefits system. So in 2019, we launched our Benefits Advice Service. Since then, we've assisted with over 7,000 queries from people affected by MS.

Your donations and support fund this crucial service.

Thanks to you we estimate we've helped people who contacted the service gain over £3.5 million in new benefits claimed and successful appeals.

You can call the MS Helpline for free on 0808 800 8000 (open Monday to Friday 9am-7pm) and ask to speak with a benefits adviser.

If no one's available, you can leave a voicemail message and we'll get back to you as soon as possible.

You can also email us on **msbenefitsadvice@dls.org.uk** or visit **mssociety.org.uk/personal-independence-payment** for information and support.

“I’m so grateful to your wonderful team. You really make a difference to people’s lives.”

Gary was diagnosed with relapsing remitting MS aged 30. Read his experience of the benefits system and how the MS Society Benefits Advice Service helped.

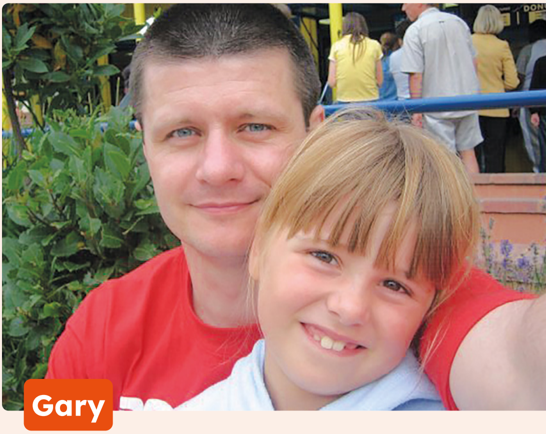
I was forced to take early retirement in 2022 due to the cognitive impact of MS. I was relying on my privately-funded pension and so I investigated PIP and applied.

The PIP assessment is points based, which means you score points depending on how you perform different activities. To be entitled to the standard rate of the daily living component, you need to score at least eight points. Unfortunately, I was awarded only two points.

Following the advice available on the MS Society website, I applied for a mandatory reconsideration and was again granted only two points. I contacted the Benefits Advice Service and spoke to Rachel. She gave me hope and the confidence to carry on by requesting a face-to-face tribunal.

I continued to reference the documentation on the MS Society website that goes through what happens on the day and it helped me to stay strong.

At the tribunal I was awarded a total of 22 points, including four points for the mobility section, which I hadn't even applied for. So, in relation to daily living, I was awarded 18 points and I therefore qualified for the high-rate award. It's as if a weight has lifted from my (rather weak) shoulders after the months of worry.



Gary

I’m enjoying my retirement much more now I have fewer financial worries. I also feel somewhat vindicated that I'm not "copping out" by retiring. It's such a relief and I'm so grateful to your wondeful team. You really make a difference to people's lives.

Campaigning to get MS on the agenda

Thanks to donations from supporters across the country, we made sure the voices of those affected by MS were heard.

During the general election, we made sure MS was part of the conversation. Together, we sent thousands of emails to candidates across the UK and over 13,000 of you signed our open letter to the new Prime Minister to make sure MS is on the agenda. Last month we alongside members of the MS community, Kerry, John and Phoebe (pictured) went to 10 Downing Street to hand in our open letter.

Our general election co-production group played a vital role in shaping our campaign before, during and after the general election. By volunteering their time, the group helped to refine our messages, define what we called for in our MS manifesto and suggest ideas for how we could support the wider community to get more involved.

Carla, a member of our general election co-production group from London.

"There's huge value in sharing lived experience and we're genuinely the experts on our condition. There are often detailed aspects of living with MS that, without lived experience, would likely be lost, minimised, or even dismissed. That awareness can help to bring about change or a new approach, and I'm all for that."

To hear more about the hand in visit **mssociety.org.uk/open-letter**

13,000 of you signed our open letter to Keir Starmer and here's a snapshot of what we sent...

Dear Prime Minister,

As Prime Minister, you have the opportunity to lead a government that transforms the lives of the more than 150,000 people living with MS right now. Will your government be one that delivers the change that can't wait any longer?

Right now, too many people with MS face unimaginable difficulties.

Broken PIP assessments and inadequate benefits, coupled with a lack of workplace support, mean many people face huge financial uncertainty. People are also missing out on essential specialist care that means the groundbreaking treatments that can support people to live well for longer are out of reach for too many. Limited resources, staff shortages, and a postcode lottery leave many feeling abandoned when they need support the most. We can't afford to wait any longer. People with MS deserve better.

The next UK Government must:

- Make sure people have financial security and the opportunity to succeed in work,
- Make sure people have the support and healthcare they need to stay healthy and live well for longer.

By taking these steps, the next government could transform the lives of those living with MS. People living with MS are counting on you.

The MS community are at the heart of our campaigns and without your support we wouldn't be able to campaign on the issues that matter most to people living with MS, thank you!

Highlights of the year so far...

This June **the MS community celebrated pride across the UK.**
Pride month is a celebration of how far LGBTQIA+ rights have come. But it's also a time to look at the challenges LGBTQIA+ communities face right now. And the LGBTQIA+ MS community is no different. We marched across London, Cardiff and Belfast. Thank you to everyone who walked, rolled, strolled, waved and cheered with us!

In April we marked **MS Awareness Week**.
For the second year running we teamed up with MS Together, MS Trust, MS-UK, the Neuro Therapy Network, Shift.ms and Overcoming MS to create one unified campaign, MS Unfiltered.

The campaign shined a light on the MS topics that can feel taboo or difficult to talk about. And encourage and empower people with MS to speak up and get support when they need to.

A big thanks to supporters like you who've made these things possible!

Our annual Stop MS Lecture took place in June and was led by Professor Thora Karadottir who is a co-lead of our MS Society Cambridge Centre for Myelin Repair. Watch the lecture here **mssociety.org.uk/annual-lecture**

The Stop MS Appeal is our campaign to raise £100 million to find treatments for everyone with MS.

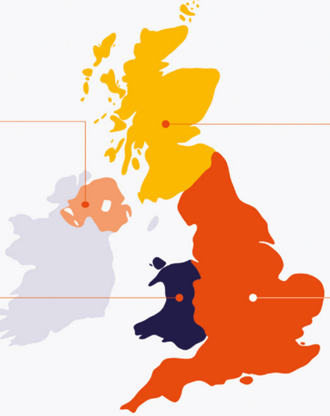
New MS propensity figures

Our new study shows that the number of people living with MS in the UK is now **estimated at over 150,000**. The previous figure, based on data from 2019, was more than 130,000. All four UK nations have seen a rise in the number of people living with MS.

There's been a 15% increase in England, 10% in Scotland, 9% in Northern Ireland and 8% in Wales. This data helps us understand more about the MS population, which is vital to our work and supporting people living with MS.

Visit **mssociety.org.uk/ms-in-the-uk** for more information.

Number of people living with MS in the UK



5,334
In Northern Ireland (that's 1 in every 350 people)

17,406
In Scotland (that's 1 in every 300 people)

6,111
In Wales (that's 1 in every 500 people)

123,442
In England (that's 1 in every 450 people)

MS Society 2024. The Health Improvement Network (THIN) Database (A Cegedim Proprietary Database). This work uses data provided by patients and collected by the NHS as part of their care and support.

Fundraising across the UK


Mel Daniels

Supporters like you do amazing things to help the MS community all year round. Whether it's taking part in a challenge, playing the Weekly Lottery or leaving a gift in your will, you're amazing! Read some inspirational stories from 2024 so far...

"What an awesome charity to jump for!"

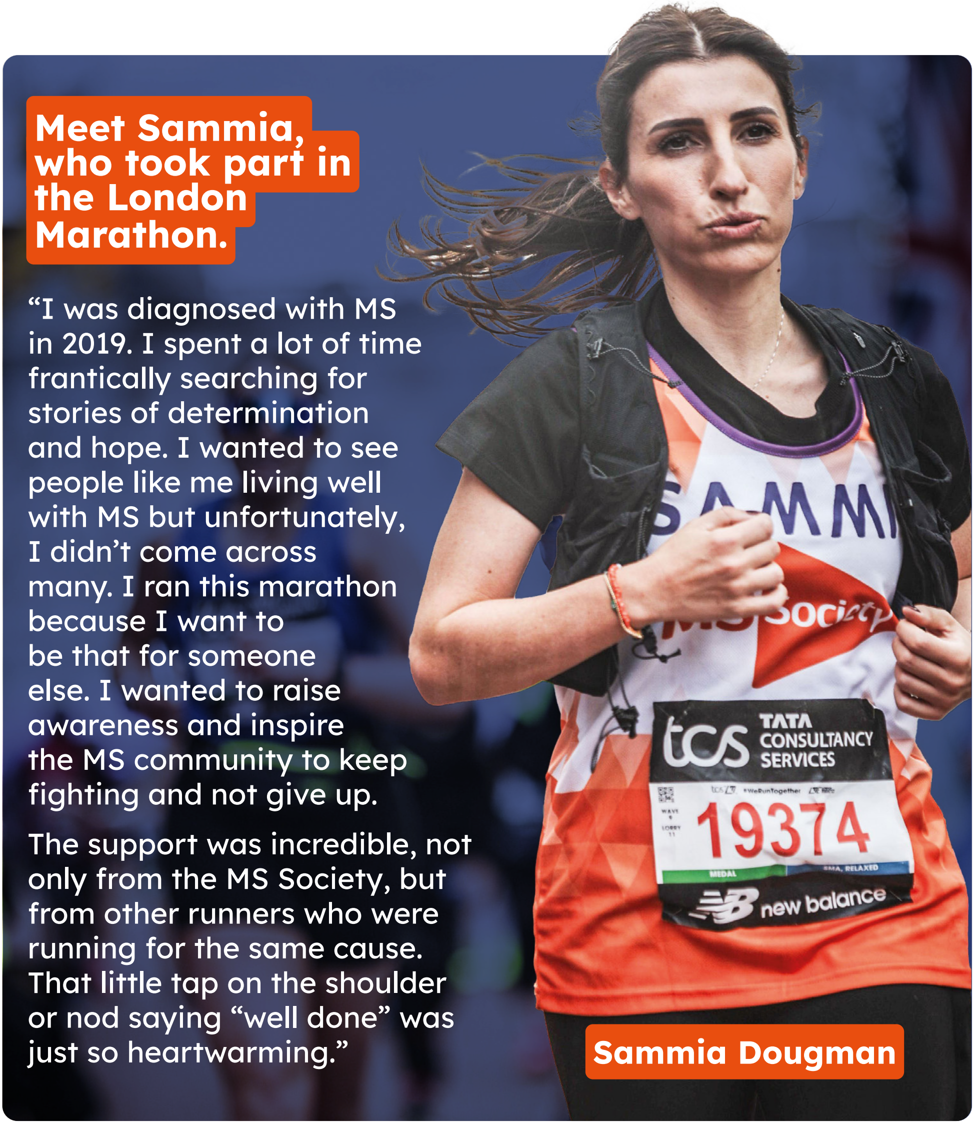
Mel Daniels took on an exhilarating skydive challenge, inspired by a desire to conquer her fears and support our work. Read about how she got on.

"Having been diagnosed myself with MS in 2019 after years of random symptoms, I'm very lucky to get the best treatment to keep these symptoms and the progression of my condition somewhat under control. MS is a very frightening condition, and without charities like the MS Society, medication wouldn't advance as much as it has done over the years.

My life could be so very different right now. I've always been too scared to register for a skydive, but when I turned 40, for some reason I felt extra brave! What an awesome charity to jump for!"

Mel conquered her fear on the day and already wants to do it all over again! If you've ever wanted to push your boundaries and support us, consider joining our next skydive challenge!

Every leap from the plane is a leap towards better treatments and support for those living with MS.



Meet Sammia, who took part in the London Marathon.

“I was diagnosed with MS in 2019. I spent a lot of time frantically searching for stories of determination and hope. I wanted to see people like me living well with MS but unfortunately, I didn’t come across many. I ran this marathon because I want to be that for someone else. I wanted to raise awareness and inspire the MS community to keep fighting and not give up.

The support was incredible, not only from the MS Society, but from other runners who were running for the same cause. That little tap on the shoulder or nod saying “well done” was just so heartwarming.”

Sammia Dougman

Get involved by emailing fundraising@mssociety.org.uk or visit our website mssociety.org.uk/get-involved And check out our dates for your diary on page 15.

Celebrating gifts in wills

A huge thanks to all the amazing supporters who have already chosen to include a gift to us in their will. These gifts fund almost half of our work and give those living with MS real hope for the future.

Lyndsey was a researcher with a PhD in molecular cell biology. In 1999 she was diagnosed with MS.

She's including a gift in her will to help us continue our ground-breaking research. She said helping improve the lives of those living with MS in the future "Just feels right". Thank you Lyndsey!

To find out more about leaving a gift in your will visit mssociety.org.uk/gifts-in-wills or email legacies@mssociety.org.uk

Write your will for free this September. We've partnered with Octopus Legacy so you can write your will for free. Write your will online and have it checked by a legal expert. Visit **will.octopuslegacy.com/advances**

It's a Win Win!

Our wonderful lottery and raffle players have raised over £150,000 so far this year.

"I live with MS myself so it's a cause that's very close to my heart. I'll be using my winnings towards getting a new mobility scooter, which is just brilliant".
Richard Stevens,
Lottery Winner

"Many thanks for the cheque. Having had MS for 30 years and supported the MS Society in all that time, it's great to have won a superb prize to enjoy a special treat. Thank you".
Allan Binns,
2023 Summer Raffle Winner

If you'd like to enter and be in with a chance of winning £10,000 visit **mssociety.org.uk/lottery**

Dates for your diary

Here's what's coming up

28 Sept	MS Walk Glasgow
Oct	My MS Woof! We're asking you to walk, roll or stroll 130km with your furry friends this October. Find out how to get involved **mymswoof.mssociety.org.uk**
7 Oct	Our Christmas Raffle goes live! Don't miss out on your chance to win our top prize of £6,000. To take part, visit **mssociety.raffleentry.org.uk** from 7 October.
27 Oct	Halloween Big Leap To find out where you can take part across the UK visit **mssociety.org.uk/get-involved/the-big-leap**
26 Nov	I Fly indoor skydiving, Manchester
1 Dec	Zip It to Stop MS, Wales
12 Dec	Carols by Candlelight To find out more about attending, email **specialevents@mssociety.org.uk**

mssociety.org.uk/fundraising

MS Society

MS Weekly Lottery

Enter our Weekly Lottery and you could win

£10,000!

Enter **today!**

By phone **01628 820 116** (Monday - Friday 9am-5pm)

Online **mssociety.org.uk/lottery** or by **scanning the QR code**

Yes, I will support the MS Society today

1 About you

Title: First name:

Surname:

Address:

Postcode:

2 giftaid it

Just date and tick **Yes** – at no extra cost to you we will be able to reclaim 25p in tax on every £1 you donate:

☐ Yes, I would like the MS Society to Gift Aid all donations I have made in the past four years, today, and on all future donations. I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed (25p from every £1 you donate) on all my donations in that tax year it is my responsibility to pay any difference. Please note Gift Aid is reclaimed by the charity from the tax you pay for the current tax year and your address is needed to identify you as a UK taxpayer.

Today's date: ☐☐ / ☐☐ / ☐☐

☐ No, I do not qualify for Gift Aid.

3 Set up a regular annual payment by Direct Debit

I would like my annual payment of £________ to be taken on the following day of the month

☐ 7th ☐ 21st

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Address:

Postcode

Name(s) of Account Holder(s)

Sort code	Bank/Building Society account number	Service user number
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Signature(s)

Date / /

Banks and Building Societies may not accept Direct Debit Instructions for some types of account.

Return this form in the freepost envelope provided or send to MS Society
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