

Autumn 2023

MS Society

your
Advances

Your support,
your impact

Inside

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Welcome to your Advances

This December marks 70 years since our founders Richard and Mary Cave hosted the first ever MS Society meeting. So much has been achieved to help people living with MS since then, thanks to supporters like you.

Thanks to the generosity of people like you, we've been able to continue supporting the MS community through what has been a challenging year for many.

Get inspired by our supporters' Hopes for the future as a reminder of how far we've come, and what we hope to achieve with your support.

Don't miss out on the latest research update, including Octopus. And it wouldn't be your Advances without giving a special shout out to our amazing Fundraising Community, who continue to do a fantastic job raising vital funds. Our work wouldn't be possible without your support. A massive 'thank you' for everything you do. You're making a huge difference.





With warmest wishes, Nick Moberly,
Chief Executive



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Keep in touch

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



Multiple Sclerosis Society is a registered charity in England and Wales (1139257) and Scotland (SC041990), and a company limited by guarantee (07451571)

Dates for your diary

Here's what's coming up in our community



16 October

The MS Society 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 16 October.



14 December

Carols by Candlelight
To find out more about attending, email specialevents@mssociety.org.uk



30 November

Volunteer impact virtual awards ceremony

Feeling active? Or know someone who is? Whether you're cheering someone on or getting involved yourself, your support makes all the difference...



23 September MS Walk Cardiff



23 September MS Walk London



28 May-29 October The Big Leap



October My MS Woof



8 October Great Scottish Run



November Game Over for MS



For more information on the above events and to sign up, please email fundraising@mssociety.org.uk or visit our website mssociety.org.uk/get-involved

Research updates

First people with progressive MS join 'mega-trial' Octopus

To stop MS, we need to find treatments that slow or stop progression for everyone. We first wrote about our revolutionary clinical trials platform, Octopus, in 2019. Since then, amazing people like you have helped at every step in this exciting journey – donating over £500,000. Thank you! We're proud the trial team has now started recruitment at

“Octopus definitely gives me hope. [...] You don't know what's going to happen when you have MS, you don't know what the future will hold. You have to try things and see if they work.”

Alykhan Kassam,
Octopus Participant



several sites, including London and Edinburgh. This means the first few people have begun taking part.

What makes Octopus special?

Octopus will transform the way we test treatments for progressive MS. It'll make testing new treatments up to three times faster by:

- testing multiple drugs at once – and comparing them with a single control group.
- using MRI to see if a drug has potential, months before we'd see an effect of the drug on disability progression. Promising drugs stay in the trial, with hundreds more people joining the existing participants. So what would normally be two consecutive trials are delivered in one.
- adding the flexibility to drop drugs that aren't promising, and slot in new drugs as they're discovered.

Find out more, including how to join, on our website:
mssociety.org.uk/octopus.

Other research news



We're currently funding 45 active research projects. They cover a wide range of topics, from looking at cells in a lab to carrying out studies with people living with MS to find new treatments. Read on to find out more about the most recent discoveries!

Myelin-making in different parts of the body

Professor Anna Williams and her team study cells that make myelin. Myelin, the protective coating around nerve fibres, gets damaged in MS.

This year, the team found cells in the spinal cord make myelin in a slightly different way to cells

in the brain. That's important because myelin repair of spinal cord lesions is less successful than in brain lesions. So, if myelin-making cells behave differently in different parts of the body, some drugs might be more effective for some cells than for others.

How astrocytes help with myelin repair

Meanwhile, Professor Veronique Miron and her team study another brain cell called astrocytes. They found astrocytes keep myelin-making cells alive by giving them cholesterol. They found boosting the cholesterol-giving properties of astrocytes improved myelin repair. It means drugs targeting astrocytes might be promising candidates to help with myelin repair.

What's next?

Together, research like this could lead towards new approaches for myelin repair. And ultimately lead to new treatments for people with MS. Look out for more on myelin repair later this year.

And we want to thank you for your contribution to this – because none of this would be possible without your support!

Victoria's lasting legacy



Victoria was diagnosed with MS over 20 years ago and has now decided to leave a gift in her will to the MS Society. She tells us how the charity has supported her, and why leaving a lasting legacy is so important.

“I don't know where I'd be today without the help and support I've received from the MS Society. They've provided a listening ear and information that's been invaluable in helping me understand and deal with my MS. It's so great to be able to just call the MS Helpline and speak to someone, knowing I can talk for as long as I like and they will listen.

The MS Society also helped me when I realised I didn't have a will. And making one has brought me peace of mind, knowing that whatever happens in the future, my wishes are fully outlined and what I want to be done with what I own is clear.

“The MS Society stood by my side.”

Victoria

Getting MS was a fearful shock, and then the MS Society put a leaflet through my door. They reached out to me when I was struggling to come to terms with how I would live with my MS diagnosis and helped me get through it. They had conversations in a quiet calm way, and if I had questions they had the answer or would come back to me with what I needed.

They didn't leave me on my own, they stood by my side and reassured me that on the lonely journey I was about to take, someone would be walking it with me and I wouldn't be alone.

The information in their magazines is useful and includes some great articles. The ones that make you smile and think of new ways around problems are always my favourites.

If the gift in my will can help the MS Society to enable people like me learn more about this condition and contribute towards making sure that those calming people on the helpline continue to be there, then I will be extremely happy."

“The MS Society really does help people like me live better with MS.”

If you, like Victoria, want to help make sure that no one in the future has to deal with their MS alone, you too might want to consider including a gift to the MS Society in your will. Just call Ilkay on 020 438 0828 or email legacies@mssociety.org.uk to learn more about our free will writing services or order a copy of our free will guide.



Together we can make sure no one has to face MS alone

Thanks to your support, we've done amazing things



Here are a few highlights of 2023 so far that you've helped make happen



Octopus launched!

We're proud to fund the first-ever multi-arm, multi-stage trial for progressive MS which officially started opening its doors to participants this year.



The First Minister has given his support in principle to the removal of the 20m rule in Scotland. Thanks to you, campaigning has continued and we're one step closer to having this rule removed!

#MSMakesMe

For the first time ever, we came together with six other amazing MS charities during MS Awareness week to shine a spotlight on MS. We teamed up with MS Trust, Overcoming MS, MS Together, Shift.ms, MS-UK and Neuro Therapy Network to launch #MSMakesMe. Together, we shared incredible stories from our community across the UK.



Our award-winning Helpline has answered over 12,000 calls so far this year.

Thanks to your support, our amazing team of advisors and volunteers can continue to give emotional and practical support to people who need it.



The Carer's Leave Act was passed, and supporters like you played a key role by sharing your experiences.

Thanks to everyone who took part in our 2019 Friends and Family of People Living with MS survey. We were able to give this crucial insight to Parliament to help make this happen.



Thank you!!

Messages of hope



In March we wrote to you and asked you to share your hopes for how Octopus could change the lives of people living with MS in decades to come. We were overwhelmed with the response. Here is a snapshot of the inspirational messages we received...

To take away the fear of MS and to give hope to those who have been diagnosed, as well as to their families.

I would like to see advances towards controlling progressive MS.

With MS, we need certainty. That's what I hope for from Octopus.





As a person living with MS myself, this trial gives me hope for my future that I could be one of many that could have a better life ahead.

So patients like my husband can live a better life.

That anyone who is diagnosed with MS can live with hope.





Our fight to change your rights to disability benefits

This autumn, we're speaking up on how disability benefits need to change.

Personal Independence Payment (PIP) should cover the extra costs of living with MS - like adapted vehicles or physio. Instead, it's costing people their time, their health, and their independence.

The PIP system has been in place for 10 years. But it's still failing people with MS. The MS community told us the process of claiming PIP is incredibly stressful. And it takes a toll on their time and, in some cases, their MS.

MS is unpredictable and different for everyone. Symptoms can be invisible or change from day to day. But PIP assessments don't take this into account. And this leads to people with MS losing out on the support they need or having to face appeals and tribunals.

It's not right for people with MS to spend months fighting for support. And often they still end up without what they need.



We've had some important wins in our campaigning so far on PIP. Earlier this year, the UK Government released a paper on its plans for disability benefits. These proposals say they'll test out matching people with assessors who are specialists in their condition. They'll also test automatically sharing assessment reports with claimants. We've been campaigning for this for years.

There's still a lot that needs to change. But this shows we can win again, if we come together.

That's why we're launching a campaign to fix PIP once and for all this autumn. We'll be calling on politicians to commit to fixing PIP. And we'll be looking for your support, so keep an eye out for the campaign in September.

**Join thousands of people campaigning to make a difference for people living with MS by becoming a member of our campaigns community.
Email campaigns@mssociety.org.uk to get involved.**

Fundraising across the UK



Fundraisers like you are crucial to our work. And we wanted to highlight some of our inspirational fundraising superstars...

Catherine Lithgow

who takes part in the Glasgow Kiltwalk every year with her two friends, Lois and Kirsteen. Her secret to success? Her fabulous decorated trolley filled to the brim with snacks that keep them all going. This year Catherine opted out of the Mighty Stride route and took on the Big Stroll so all 3 could take part as a team. In total she's raised over £9,000 for the MS Society in the last 10 years!



Fiona who did MS Walk Manchester, raised £900 and has matching funding from Capita which will push her sponsorship to £1125. "The kids found the treasure hunt on the back of the map very engaging, and we didn't get a single 'Are we nearly there?' until after we found the last one! I would also like to say how much fun the event was, really well organised and the staff were lovely. The water stop at the Chinese Arch was greatly appreciated!"





**Paul
and**

David Smith, who started a 15-day challenge to complete the 192-mile Wainwright Coast to Coast walk. They said “More than 130,000 people in the UK have MS, and one of those is particularly close to our hearts, my daughter Francesca. We have some great memories of the challenge and the kind people we met along the way who referred to us as ‘The Sunderland Lads’. We are delighted to say to date we have raised £3,858.”



The public-sector body SCAPE hosted a charity football tournament at Nottingham Power league to fundraise for MS Society in May. “It was a fantastic day to bring construction partners together, raise awareness around multiple sclerosis and discuss how MS Society can make a difference. The event raised a total of £3,855”

Thank you to all of the **100s of incredible MS Superstars** across the country who have fundraised this year. Your efforts will bring us closer to our vision – a world free from the effects of MS. You are amazing!



**Thank
you!**

For information on doing your own fundraising event, email fundraising@mssociety.org.uk or visit our website mssociety.org.uk/get-involved



MS Society

◀ **From showing support today
to changing lives tomorrow** ▶

Our free will-writing service can take you there

If you, like Laurence and his family, want to stop MS, why not take advantage of our free will-writing offer today? An up-to-date will is the best way to make sure your final wishes are clear, and any gift you include will help stop MS for future generations.

**For more information or a free guide to
will-writing, contact Ilkay on 020 438 0828
legacies@mssociety.org.uk or visit
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