MS
MATTERS
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RESEARCH
Revolutionising the clinical trials landscape

NEWS
Our response to disability benefits proposals

INSIGHT
How does ageing affect myelin repair?

THE JOURNEY TO NEW TREATMENTS

10 years of our Stop MS Appeal

MSM006 • SPRING 2025 • ISSUE 149

MS Society

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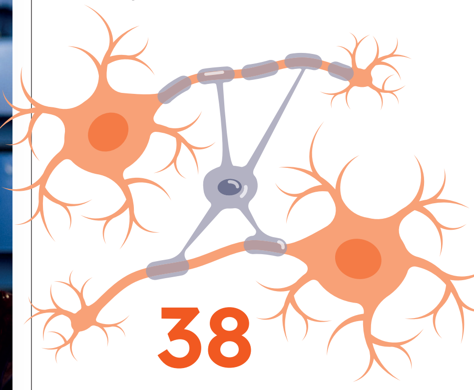

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Latest info

We've updated our printed booklets to help you claim benefits you're entitled to:

- **Benefits and MS**
  a brief introduction to different benefits
- **Claiming Personal Independence Payment (PIP)**
  a step-by-step guide
- **The Work Capability Assessment (for ESA and Universal Credit)**
  a step-by-step guide

Download or order at **mssociety.org.uk/publications** or call **0300 500 8084 (select option 4)**.

You can find tips on claiming and managing the cost of living at **mssociety.org.uk/benefits**

And you can speak with our Benefits Advisers through our Helpline on **0808 800 8000** or by emailing **msbenefitsadvice@dls.org.uk**

The UK Government plans to make changes to PIP and Universal Credit from next year. We'll update our information when those changes apply.

Right now you can find out the latest on our website or by calling our Helpline.

SPRING 2025 - ISSUE 149

Welcome to the first MS Matters of 2025. In this issue, we're celebrating the final year of the Stop MS Appeal. I joined the MS Society the same month the Appeal went public and we shared the incredibly powerful stories of people like Donna and Nikki, who you can read about on page 26.

Since then, I've seen how the Appeal has put MS research right at the heart of the MS Society. It's been so much more than a fundraising campaign. It's brought people together.

Amazing fundraisers like Yvonne and Duncan who work tirelessly to raise funds for our Cambridge Centre for Myelin Repair (page 49). Researchers like Stavros, whose work at the Centre you can read about on page 38. And people with MS who take part in research, like Jacqueline, a clinical trial participant who chats to trial leader Professor Jeremy Chataway on page 14.

Research can be incredibly frustrating – the seemingly slow pace, the inevitable setbacks. But bit by bit research is going to give us the answers we so desperately need, and stop progression for everyone with MS.

If you'd like to talk about any of the topics in this issue, please call our MS Helpline for free on **0808 800 8000**. We're here to support you.

Catherine Godbold
Senior Research Communications Manager

One donation. Double the impact.
You're critical to the success of the MS treatment revolution. To help us hit our £100 million Stop MS Appeal target, two generous supporters have agreed to match every £1 donation you give. That's up to a total value of £250,000. Donate before Sunday 27 April to double your impact. Your donations can help turn world-leading research into life-changing treatments. Visit **mssociety.org.uk/match** or use the QR code.


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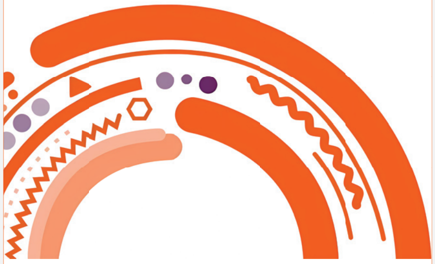
Navigating MS conversations

During MS Awareness Week (28 April – 4 May), we'll be teaming up with seven other MS charities to shine a spotlight on MS conversations.



MS Awareness Week is a team effort. This year, we're working with:

- MS Together
- MS Trust
- MS-UK
- Neuro Therapy Network
- Overcoming MS
- Shift.ms
- Talks with MS

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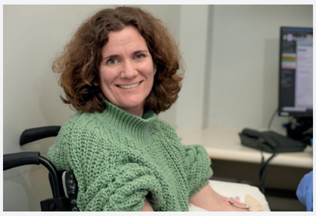
Living with MS is different for everyone. But no matter how it affects you, we all have conversations about MS.

Talking about MS isn't always easy. Whether you're trying to explain the condition to family members, asking an employer for reasonable adjustments, or opening up to a new partner. Finding the right words can be difficult. And you might not always feel understood.

Over the past few months, we've been working with a diverse group of volunteers from the MS community. They've told us loud and clear that they want more support and resources to help them talk about MS.

Ailsa Guidi from Haslemere, who lives with secondary progressive MS, is one of these volunteers.



Ailsa Guidi from Haslemere, is a volunteer

She says "MS conversations happen all the time. When you have invisible symptoms, you're constantly having to remind people about them. And if you've got a visible symptom, you're constantly addressing people's prejudices or their lack of understanding.

"Being part of the co-production group itself was a really good example of the importance of conversations. So many positive things came out of the discussions between us."

Throughout the week we'll share stories from our community and resources to help you navigate challenging MS conversations.

FIND OUT MORE ABOUT... MS AWARENESS WEEK

If you'd like to get involved or learn more about what's happening during the week visit mssociety.org.uk/ms-week

Disability benefits: what you need to know

How we're speaking up and supporting the community.

The UK Government has proposed changes to disability benefits which could affect some people with MS. What's proposed could make it harder for some people to get Personal Independence Payment (PIP) or affect how much Universal Credit they get. Changes to PIP won't apply in Scotland.

We know this is a worrying time for lots of people. You can find out what we know already and get support and information on our website or from our Helpline.

What we're doing

We're calling for the Government to scrap proposals to cut benefits that provide a lifeline for so many people. Through our campaigning against these cuts, we're making sure all our voices are heard. Keep an eye on our social media channels and website for more about how to get involved.

You can sign up to our campaigns list to be the first to get our campaign actions at **mssociety.org.uk/campaigns**

FIND OUT MORE ABOUT... BENEFITS

Visit our website for up-to-date information at mssociety.org.uk/benefits. Our MS Benefits Advice service offers free, confidential advice. You can get in touch by calling 0808 800 8000 or emailing helpline@mssociety.org.uk

iStock

Cladribine to be available for more people

More people with relapsing MS will have the option to take cladribine following a recommendation from the National Institute for Health and Care Excellence (NICE).

Cladribine (brand name Mavenclad) is a disease modifying therapy (DMT) taken as a tablet. The new recommendation says anyone with relapsing remitting MS who's having relapses or new disease activity visible on MRI scans (known as active MS) may be eligible for it. Previously, it was only prescribed to people with more severe active relapsing remitting MS.

England and Wales will be the first countries in Europe to recommend cladribine for more people with active relapsing MS. Decisions in Scotland and Northern Ireland are expected to follow soon.

Find out more at **mssociety.org.uk/cladribine**

Our new MS Society shop in Sale is now open!

The shop will help us raise vital funds with volunteers, donors and shoppers all playing their part.

It was an exciting year in 2024, with the launch of our shop in Altrincham, Greater Manchester. Building on this success we opened another MS Society shop in nearby Sale at the start of 2025.

The shop is based in the heart of the Sale community, on Norris Road. It offers a fun, accessible and friendly space to browse for pre-loved clothes, books, homeware and more.

We want our shops to be about much more than just shopping. We aim to create spaces to connect with the local community, raise awareness of MS and support people who live with it. Every purchase made in the shops helps fund vital research and services, making a real difference for people affected by MS.

Shop Manager Steven says "Myself and the team are very excited about the new shop and we're determined to make it a success. We're already getting our name out there and look forward to welcoming more shoppers and volunteers over the next few months. We're very proud to represent the MS Society in the Sale community."

Steven
MS Society Shop Manager

Shop heroes wanted

If you fancy a new challenge, we're looking for shop heroes to join our team! Volunteering is a great way to gain experience, meet new people and work in a fun and welcoming environment. Even if you only have a few hours to spare, volunteering in one of our shops will have an impact on people affected by MS.

FIND OUT MORE ABOUT... OUR SHOPS

Are you interested in visiting our shops, donating unwanted items or offering your time?
Find out more at
mssociety.org.uk/our-shops

A year of events for Stop MS

We're hosting some very special events in 2025 to celebrate the final year of our Stop MS Appeal.

Find out about all these fundraising events and more at **mssociety.org.uk/get-fundraising**

TUESDAY 24 JUNE
Kings Place,
London N1 5AG

Stop MS Appeal Annual Lecture

Professor Alan Thompson will present our 2025 Stop MS Annual Lecture, followed by a panel discussion with our Scientific Ambassadors.

Professor Alan Thompson is Dean of the UCL Faculty of Brain Sciences and an honorary consultant neurologist at the National Hospital for Neurology and Neurosurgery, Queen Square. He's been researching progressive MS for forty years, focusing on the diagnosis, evaluation and management of these forms of MS.

If you can't come to London, the lecture will also be live streamed on **youtube.com/mssociety**

To register your interest please email **specialevents@mssociety.org.uk**

VARIOUS DATES THROUGHOUT THE YEAR
Six exciting cities around the UK

Walk, roll or stroll to stop MS

There are a range of distances – starting from 1km – and each event is accessible for wheelchairs and pushchairs. All the money you raise will go to our Stop MS Appeal to fund ground-breaking research.

Find out more at **mssociety.org.uk/ms-walk-2025**

MS Walk 2025 dates	
Manchester	Saturday 17 May
Belfast	Saturday 7 June
Birmingham	Saturday 14 June
Glasgow	Saturday 13 September
Cardiff	Saturday 20 September
London	Saturday 27 September

Maisie's MS Walk

Natalie and her daughter Maisie, aged 11, are taking part in the MS Walk in Cardiff in September. Natalie says "My mum has had MS for almost 30 years and had a secondary progressive diagnosis seven years ago. Since then, her health has declined quite rapidly.

"Maisie was amazed when she found out I'd raised money for the MS Society before she was born by taking part in a skydive. She's been looking for a way to fundraise herself. She's also persuaded our aunties and cousins to join us. We're hoping to raise £1,000.

"Although it's too late for any medication to make a difference for my mother, I hope research will help other people with MS. Hopefully, one day, MS will be a thing of the past."

THURSDAY 4 DECEMBER

Central Hall Westminster, London
SW1H 9NH

Carols by Candlelight

Our annual concert promises to be a wonderful evening of festive cheer as we celebrate the end of the Stop MS Appeal.

This year's event will happen in a fabulous new venue. And it'll be filled with Christmas delights, including appearances from celebrity guests, your favourite carols and inspiring music.

Emily Revess, MS Society Trustee, attended our 2024 Carols by Candlelight concert. She said "It was absolutely amazing and I was blown away by the joy and celebration. The choir and speakers were wonderful and I was beaming throughout. These kinds of events make me really proud to be a Trustee and see the community come together."

To register your interest please email **specialevents@mssociety.org.uk**

Diary dates

ACTIVITIES

UNTIL SUNDAY 27 APRIL

Double the impact

Did you know that if you donate to the Stop MS Appeal by 27 April, your donation will be doubled? Two generous supporters have agreed to match every £1 donation you give, up to a total value of £250,000.

mssociety.org.uk/match

SATURDAY 6 SEPTEMBER

Zip It to Stop MS

Experience the thrill of the world's fastest zipline and raise funds to stop MS at Zipworld, Penrhyn Quarry, North Wales.

mssociety.org.uk/zip-it-25

SUNDAY 7 SEPTEMBER

Great North Run

Take part in Newcastle-upon-Tyne's legendary half marathon and raise funds for vital research.

mssociety.org.uk/great-north-run-25

WEBINARS

TUESDAY 22 APRIL, 6PM

Progressive forms of MS

This monthly peer group session is for people living with progressive forms of MS. It's a chance to meet others, chat and share.

mssociety.org.uk/peer-group

THURSDAY 15 MAY, 6.30PM

Rest, recharge and repeat: the importance of sleep

Explore practical ways to enhance your sleep quality with sleep expert Dr Neil Stanley.

mssociety.org.uk/sleep-webinar

See our programme of webinars and information events at mssociety.org.uk/virtual-support-events


Independence

Researchers create an ‘atlas of MS brain cells’

This work could help personalise MS treatment

Working as part of an international team, researchers at our Edinburgh Centre for MS Research have created an ‘atlas of MS brain cells’. The team analysed brain tissue donated by people with MS after they died – including tissue from the MS Society Tissue Bank (see page 37). They found they could separate people with MS into four groups based on how their brain cells behaved.

MS affects each person differently. Research like this could pave the way for more personalised treatment of MS, rather than using a one-size-fits-all approach.

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Professor Anna Williams, co-lead of the MS Society Edinburgh Centre for MS Research, led the study.

“This is such an important discovery as it tells us that we can put people with MS into subgroups according to what’s going on in the brain at a molecular level. And these subgroups might respond to therapies differently.

“So far, we have observed these subgroups using post-mortem brain tissue. To help treat MS, we need to work out how to group people with MS using blood tests. We could then design clinical trials specifically for these subgroups, which could help us get the right drugs to the right people.”

Find out more at mssociety.org.uk/atlas-brain-cells

Revolutionising the clinical trials landscape together

What the Stop MS Appeal means to us

We asked consultant neurologist, Professor Jeremy Chataway, and Jacqueline Krarup, who lives with secondary progressive MS, what the research made possible by the Appeal means to them.

Professor Jeremy Chataway is Professor of Neurology at University College London and the National Hospital Queen Square. He's led three ground-breaking clinical trials supported by the Stop MS Appeal.

It's been very emotional to be able to do what we've done in the last 10 years thanks to the Stop MS Appeal. To come from zero, which is where we were, to where we are now.

We've been able to bring to life a clinical trials network that just didn't exist before. Now we have a whole trials arena we can use to test the most promising drugs and finally do something for progressive MS.

It's been shown across medicine and in MS, in particular, that being part of a trial can be really valuable. Being able to engage with doctors and nurses regularly, often getting more scans and tests, and being part of a community. Now people with progressive MS finally have that opportunity.

A united team

Everyone working as a united team and moving in the same direction has been exciting. We're taking inspiration from other conditions where they've made breakthroughs. We're part of the International Progressive MS Alliance. And excellent lab scientists are working on progressive MS around the UK. Now we can show them their work won't just stay in the lab. We'll move it on and test it with people with progressive MS.

I can't think of anywhere else in the world doing this. It's putting the UK on the map.

An immense project

Of course there's profound disappointment with the MS-STAT2 results, which didn't show an effect on slowing progression. But we're learning more about what progressive MS is all the time. There are so many benefits beyond

Our Stop MS Appeal helps to fund clinical trials. To support clinical trials like these visit **mssociety.org.uk/research-give**

> In 10 years, I want to have a medicine in my hand that really does reduce progression. I don't think that's unrealistic

the top-line results.

MS-STAT2 was an immense project, successfully delivered even through the pandemic when many trials closed. Nearly 1,000 people with progressive MS took part for four and a half years. It gave us the confidence to move on to an even more ambitious trial: Octopus.

An optimistic future

The problem of progression is even more relevant now. It's been revealed that the changes causing progression happen right from the beginning. It's at the core of what MS is.

We're realistic. If it was straightforward, it would be done already. But in 10 years, I want to have a medicine in my hand that really does reduce progression. I don't think that's unrealistic.

It takes time. Everyone's trying their best. And the Stop MS Appeal provides the fuel.

>

Jacqueline Krarup, who lives with secondary progressive MS, has taken part in two of those trials.
MS-STAT2 was my first experience of a trial. And once you get involved, you can't not be. So going on to join Octopus was personally a no-brainer.

The benefits of taking part

The amazing care and attention I received from being on the trials, practically and emotionally, made such a difference to my state of mind. That's what the trials have given me, and my sister, who's also part of Octopus.

It's really helped with my understanding too - what can and can't be done for progressive MS. I know there's no such thing as a cure, but it's how you can live your best life.

I know there's work being done to make it so more people with MS have the chance to join these trials. The methods for doing MRIs are becoming less cumbersome. And with Octopus, some of the tests can be done at home. People can take part who couldn't before. People who use a wheelchair. People who are older.

Learning

I think it's also about being realistic. It's such a tough nut to crack. I remember the conversation I had with Jeremy when the MS-STAT2 results came out. You feel disappointed. But we've learnt so much from the findings that did come from it, about the biology of MS and where we go next.

One thing I've found really interesting since the beginning was the communication between researchers. Not just within MS circles, but other conditions too, learning from what worked there. And the international aspect too.

> “These trials give me hope that future generations won't be affected in the same way

Hope for everyone with MS

My MS has progressed, so hopefully Octopus will find something to slow it down. But more importantly, these trials give me hope that future generations won't be affected in the same way. I see a future where people with MS may not even reach the progressive stage. I'll keep holding Jeremy to account to make this a reality!

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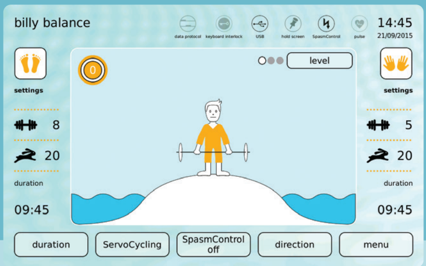
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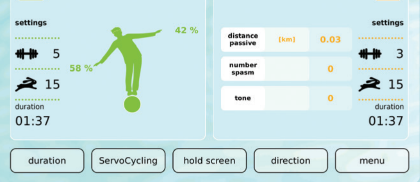
Interactive gaming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number spasm 0
tone 0
settings 3, 15, duration 01:37

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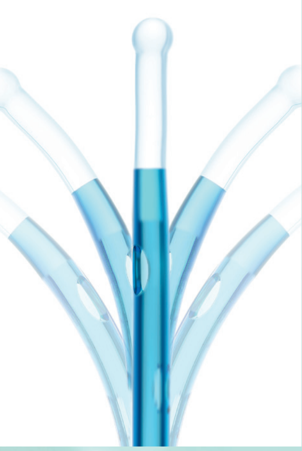

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www.manfred-sauer.co.uk

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Reaching recruitment milestones

Clinical trials are a crucial way of testing potential new treatments for MS. Thanks to the MS community and our clinical trial teams, we've reached recruitment targets for three of our ongoing trials.

Our Stop MS Appeal helps to fund these clinical trials. To support clinical trials like these visit **mssociety.org.uk/research-give**

Octopus

Octopus, the world's first multi-arm, multi-stage trial for MS has recruited more than 375 people with progressive MS to its first stage.

We've reached this goal two months ahead of schedule. This is thanks to an incredible response from the MS community and the hard work of our Octopus trial sites. Recruitment began in January 2023 in London. And we now have 15 sites across the country with plans to expand to 30.

The trial will now move seamlessly into the next stage, aiming to recruit up to 1,500 more people with MS. In this stage, Octopus will continue to test the same treatments: metformin and alpha lipoic acid. Existing participants will remain in the trial. And sites will continue contacting people who've already registered their interest in taking part.

ChariotMS

The 200th person has joined the ChariotMS trial, reaching our recruitment goal. The first results are expected in 2027.

The phase 2 trial is testing whether cladribine can help people with advanced MS maintain arm and hand function. Traditionally, MS clinical trials have used walking ability as the main measurement of whether a drug is effective. This excludes people who use wheelchairs. ChariotMS offers some people who've never been eligible the chance to take part in a clinical trial.

CCMR2

The 70th person with MS has joined our phase 2 myelin repair trial in Cambridge, reaching our recruitment goal. Results are expected later this year.

The trial is testing a combination of the drugs metformin and clemastine in people with relapsing MS. Researchers want to know if these drugs can improve myelin repair. Participants will be monitored for six months using tools like MRI to look at the drugs' effects on the brain. If results are positive this will pave the way for a larger trial to see if this drug combination can also impact disability.

FIND OUT MORE...ABOUT TAKING PART IN RESEARCH

MS research wouldn't happen without the people who take part in clinical trials. Read more about what it's like to be in a study at **mssociety.org.uk/trials**

Looking back on 10 years of the Stop MS Appeal

Our Stop MS timeline

We launched our Stop MS Appeal back in 2015. Our goal? To raise £100 million for MS research. 10 years on, we reflect on the progress that's been made. And look ahead to what the future of MS treatments could look like.

2015

It all starts here!

Our Stop MS Appeal launched. We worked closely with charitable trusts, companies and philanthropists on our early fundraising efforts.

2015

Jacqueline du Pré concerts raise £1,230,755

The fundraising concerts at the Royal Festival Hall paid tribute to the acclaimed cellist who had MS and died aged 42.

2018

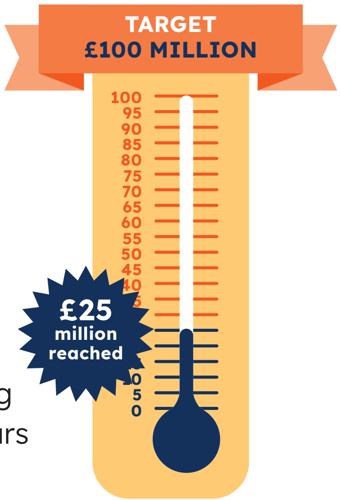
MS-SMART trial is successfully completed

Our groundbreaking MS-SMART trial found none of the treatments tested could slow MS progression. But it showed it was possible to test multiple treatments for MS at the same time. And built the foundation for our future clinical trials.

2017

£25 million raised

Thanks to the generosity of our donors, we hit a quarter of our fundraising goal just two years into our Appeal.



2018

Researchers set up an automated drug discovery platform

Professor David Lyons and his team at our Edinburgh Centre for MS Research built a unique robotic platform. This will help get drugs to clinical trials years ahead of time. Read more about the work of our Edinburgh Centre at **mssociety.org.uk/edinburgh-centre**

2019

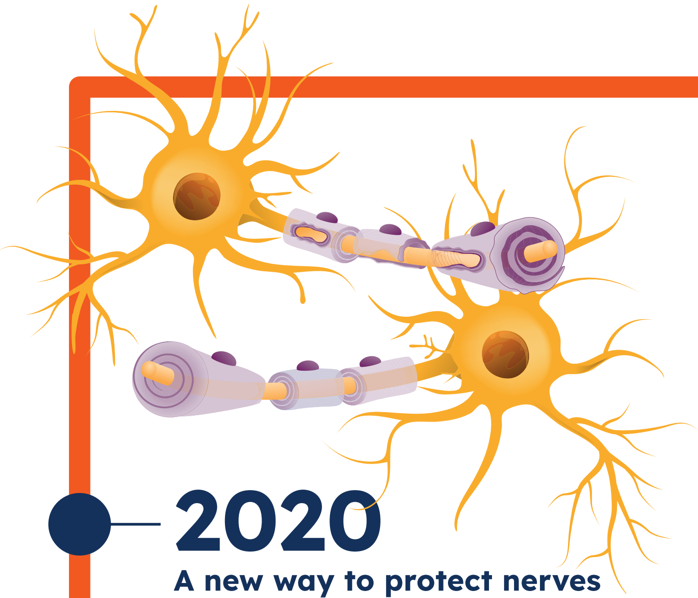
The Stop MS Appeal goes public!

We got the word out about MS research and how donations can help across TV, radio and newspapers.

2019

Ocrelizumab, the first treatment for primary progressive MS, is approved on the NHS

We campaigned to make this happen. And research from our world-leading Tissue Bank provided samples and evidence to support its development. Read more about the Tissue Bank on page 37.



2020

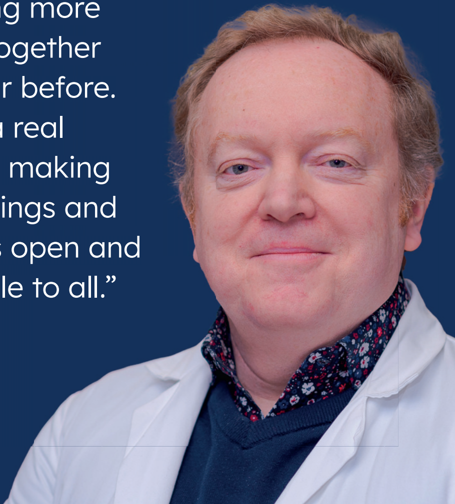
A new way to protect nerves is discovered in mice

Researchers at our Edinburgh Centre of Excellence found that an existing diabetes drug can boost energy supplies in nerves with damaged myelin. This helps protect them from further damage.

The view from the lab

Professor David Lyons, Co-Director of the MS Society Edinburgh Centre for MS Research

"Since the start of the Appeal, we've made real progress in MS research. From discoveries in the lab to the launch of Octopus. I'm incredibly hopeful for the future of MS research. The MS research community is working more closely together than ever before. There's a real focus on making new findings and progress open and accessible to all."

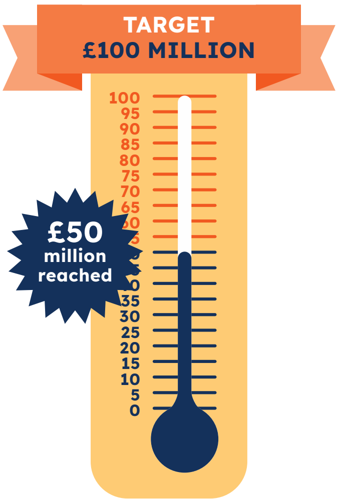


Jacob Forsyth-Davies/Shutterstock

2020

We're halfway there!

We raised £50 million thanks to incredible support from our community.



2020

Trial shows myelin repair in humans is possible

Results from our CCMR1 trial found that a drug developed to treat cancer can help repair myelin in people with relapsing MS. Scientists say this breakthrough is critical to their goal of stopping MS.

2022

Annabelle is the first person to join a new myelin repair trial

The trial is testing two drugs taken together to see if they can kickstart the body's natural myelin repair process.

2024

MS-STAT2 trial is successfully completed

Unfortunately, the trial showed simvastatin doesn't slow disability progression in people with secondary progressive MS. But it highlighted the ability of the UK MS community to deliver high-quality, large-scale clinical trials.

2024

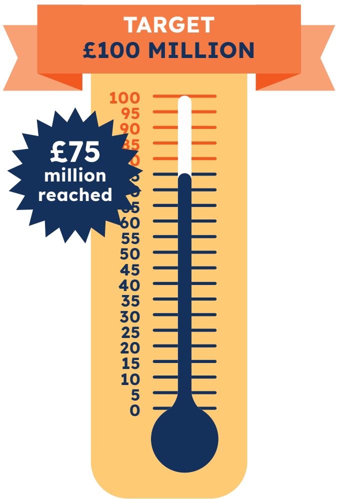
Octopus reaches its first recruitment goal ahead of schedule

More than 375 people with MS joined the first stage of the trial at 15 sites across the UK.

2023

£75 million raised!

Thanks to our supporters, we moved closer to our £100 million fundraising goal.



2023

A world-first trial launches

After more than a decade of work behind the scenes, our clinical trials platform launched. Octopus (a name chosen by the MS community) is the first ever multi-arm, multi-stage trial in progressive MS. It's designed to transform the way treatments for progressive MS are tested.

What's to come?

2025

Myelin repair trial results

We're expecting the results of the CCMR2 trial later this year. This could take us closer to a myelin repair treatment.

2025

We'll hit our £100 million target

With your support, we'll hit our £100 million fundraising target by the end of 2025.

Over to you

We asked members of our Research Network to share a research milestone from the last 10 years that was important to them.

"I was the first person on the Octopus trial at Coventry. I'm passionate about making a difference for people with MS."
Tony

"It's been good to see the breadth of research funded, from exercise related research to trials testing potential drugs."
Alison

"The research that means the most to me is anything that gets us closer to understanding how to repair myelin. There have been several very promising discoveries. I can't wait for them to be ready for bigger human trials."
Susan

LEARN MORE

If you're interested in reading more about the history of the Stop MS Appeal visit **mssociety.org.uk/stop-ms-timeline**

My life in MS research

from early career researcher to MS professor

Dave Godden spoke to Professor Julia Edgar, a researcher at the University of Glasgow who has worked in MS research for over 20 years.

Dave Godden a retired doctor, musician and fundraiser who has been living with MS for 30 years.

Hi Julia! Can you tell us how you first got involved with MS research and the MS Society?

At the University of Glasgow in 1999, I first worked with myelin, the protective coating around nerve fibres that gets damaged in MS. But I've been interested in MS since childhood when I saw a family friend affected by MS. At that time there were no effective treatments. She sadly died in her forties.

In 2004, I was awarded funding by the MS Society through an Early Career Fellowship. My work focused on understanding how nerve fibres become injured in MS. We began to learn more about how oligodendrocytes, the cells that make myelin, help support the function and survival of nerve fibres. This funding was so important to support me in the early stages of my career and it's allowed me to become an independent researcher, now leading my own team.

Dave Godden's Life Stories project has raised over £16,000 for the MS Society to date. His albums are available at **davegodden.bandcamp.com**

Why do you think it's so important to support researchers at all stages of their career development?

Scientists need drive and curiosity, and a deep desire to find answers. Early career researchers bring energy, new ideas, creativity and knowledge of the newest technologies. And more experienced researchers bring experience, a wealth of knowledge and understanding. Together, they make a great team.

How has your understanding of MS changed since you began your work?

We know much more now than we did when I started, though many questions remain unanswered. It's still a difficult condition to understand. For example, how are nerve fibres injured in MS? And how can they be protected to prevent or delay MS progression?

We've learned that damaged myelin can actually harm our nerve fibres. In the short term, losing myelin doesn't seem to cause much damage. But over time, it can be harmful. Now we're trying to better understand why injured myelin is harmful to the nerve fibres.

How can the work you do with cells in the lab ultimately help us find better treatments or ways to prevent MS?
There's no perfect way to mimic MS in a lab, but lab studies have taught us a lot about how nerve cells get damaged. For example, in my own lab, we're showing how the nerve fibres and myelin-making oligodendrocytes 'speak' to each other to maintain the health of the other. Ultimately these models in our lab provide clues about approaches to treat or prevent MS.

The Stop MS Appeal is now coming to an end. What do you think the biggest achievements in MS research have been over the past 10 years?
There have been several, but one stands out to me. 'Single cell sequencing' has helped us better understand how MS develops. It lets us look inside individual brain cells to understand which genes are turned up or down. This could lead to more personalised treatments, so each person gets the best possible care for their MS. The first time this method was used to study in MS was in 2019, and the field has moved rapidly since, with new discoveries and advances using this method.

And looking forward, what are your hopes for the next 10 years?
Ultimately, I hope MS can be prevented. But over the next 10 years I think there'll be real breakthroughs with research showing how early diagnosis and treatment can slow down the progression of MS.

> “We know much more now than we did when I started, though many questions remain unanswered

Sharing my story to stop MS

What's it like to be the public face of the Stop MS Appeal? We asked Donna, Nikki and Rozani, who've all taken part in fundraising campaigns for the Appeal.

I wanted to be seen

Donna took part in our Stop MS TV ad in 2019. She was diagnosed with relapsing remitting MS 23 years ago when she was 17.

For me, taking part in the Stop MS TV ad was about being seen. At that time, I didn't really see younger people with MS in the media.

I wanted to show that we're people with lives and dreams we want to pursue. We're trying to live, not just exist. That's what I wanted to show when you filmed me doing my make-up!

When I was diagnosed with MS, my focus was on hiding it. I couldn't see anyone else with the condition, so it felt like I was the only one. Now it feels like people are willing to share because somebody else has shared.

The actual filming of the advert was the real highlight for me. Before my MS diagnosis, I was this happy, jolly youngster who was really into performing arts. I was an A-star drama student. For me, doing the filming and going on set was like a dream come true.

In my Stop MS Appeal interview, I spoke about my love of football. I'm a huge West Bromwich Albion fan. My happy place is at a game, but I can't go as often as I'd like because the cold really affects me. I still go when I can because we should all do things that bring us joy.

I've had MS for such a long time but I'm still moving forward with hope. Lots of treatments are being researched. Not just for relapsing remitting MS, but secondary progressive and primary progressive MS too.

Nobody knows if MS is going to knock on their door. If it does, and whoever it happens to, there's now a real hope for the future.

Rebecca Cresta

For me, taking part in the Stop MS TV ad was about being seen

Fundraising makes the research possible

Rozani took part in our recent History Makers campaign for the Stop MS Appeal. She was diagnosed with relapsing remitting MS in 2019.

I had my first relapse in summer 2019 and my second in March 2020. My symptoms now include numbness, weakness and pain in my legs and arms. I also experience MS hug and Lhermitte's sign, which is like an electric shock feeling up to your neck.

In February 2024, I took part in a ballet project at the Royal Opera House through the MS Society. My husband Steven saw how happy I was. And how it brought out a positive side to the journey I was going on. He wanted to give something back, so he decided to organise a football event to raise money for the MS Society. It was a bit of a whirlwind! Our target was £500 but we raised nearly £3,000.

That's what led to us being part of the History Makers campaign. We didn't really see ourselves as history-makers. But when the campaign came together, it made me realise how important it is to raise money. And it made me so proud of Steven.

> “ Learning about the research has given me even more hope

The filming for History Makers was on our 10-year wedding anniversary. Sometimes the universe aligns these things! It made me realise it'd be very hard to do this journey without Steven. And all these amazing people who are trying to stop MS.

I also went to the Stop MS Annual Lecture last year, which gave me an insight into the research that's going on. I hadn't realised how much goes into treatments. Not just to slow the progression of MS, but to hopefully one day help with the damage that's already been done.

I'll always have hope and faith. We called our second daughter Amal, which means hope in Arabic. Learning about the research has given me even more hope. And without fundraising, this research wouldn't be possible.

If you'd like to fundraise to help stop MS, like Rozani and Steven, visit mssociety.org.uk/fundraising-ideas

The film crew had me doing Pilates while singing

Nikki also took part in our Stop MS TV ad. She was diagnosed with relapsing remitting MS 10 years ago in 2015.

My mum had MS when there were no treatments or even MRIs. She died when she was 59 in a nursing home. One of my cousins on my dad's side also had progressive MS. Neither of them had any medication. But even though it was 10 years in February since my diagnosis, I've had medication from year one. I've been on dimethyl fumarate (Tecfidera) the whole time.

That was always in my mind when I was doing the filming. I thought "This isn't about me. This is about others who can benefit if I do my best." On the day, the film crew had me doing Pilates while singing. Let me tell you, it wasn't that easy! It was surreal but a lot of fun.

Sharing my story for the video was more difficult than I thought it would be. I cried in it. Talking about my diagnosis took me back there – I was reliving those moments.

One of my hopes for MS research is that scientists can find new treatments by repurposing existing drugs. Dimethyl fumarate, the one I'm on, was originally for psoriasis.

It'd be fabulous if there was something that could stop MS in its tracks or even reverse it. Understanding its cause could unlock treatments for other autoimmune conditions, too. So it's great we're working with researchers in other areas.

In the final year of the Stop MS Appeal, I want to encourage everyone again to do something to support it, no matter how small.

> “This isn't about me. This is about others who can benefit if I do my best

Find out more about our Stop MS Appeal at mssociety.org.uk/stop-ms-info

Sky Sports commentator and former pro golfer Tony Johnstone was diagnosed with relapsing remitting MS in 2003. He talks about his experiences and how research helped him.

A clinical trial changed my life

What led to your MS diagnosis?

I woke up one morning and my left hand was numb. As the day went on, it progressed up my left arm and down my left side. And then the left side of my face started tingling and everything went numb. My first thought was "I'm having a stroke".

I went to see a neurologist the next day. He said it was a viral infection and put me on steroids.

Shortly after, I was halfway through a practice round for the Open Championship at Royal St George's in Kent. As I walked onto the tenth tee it was like somebody had pulled the plug on me. My energy levels went through the floor. I could barely walk.

The same thing happened the next day during the qualifying round. I couldn't carry on. I went back to see the neurologist and had MRI scans done. They discovered it was MS and I was told my golfing career was over.

Was that the lowest point for you?

I was absolutely devastated. All I'd ever wanted was to be a pro golfer from 12 years of age. And suddenly they tell you "You're never going to be doing that again." It's a shock to the system.

My symptoms were a complete lack of coordination. I couldn't put my hand on a door handle. I couldn't manage a knife and fork. I started losing my memory. I got to a point where I couldn't remember my kids' names. I couldn't leave the house because I'd get to the end of the drive and have no idea why I was there.

ALEMTUZUMAB

This is one of around 20 disease modifying therapies (DMTs) licensed for MS. These treatments help many people with MS have fewer relapses. They can also slow down your MS getting worse.

To read more visit mssociety.org.uk/dmt-info

> You go into hospital and they infuse you with a drug that shuts your immune system down. It was like rebooting a computer

Which clinical trial did you take part in?

It was for a drug called alemtuzumab (the brand name now is Lemtrada). There was just one place left on the trial and my neurologist managed to get it for me.

It was the luckiest break I've ever had. I received two treatments a year apart. You go into hospital and they infuse you with a drug that shuts your immune system down. It was like rebooting a computer.

For the first 10 weeks, I had to be very careful as I had no immune system. But within a couple of weeks, I noticed a big difference in my memory and coordination. And then I

> I'd been told I'd never play golf again at any decent level. To go out and win a tournament – thanks to the clinical trial – felt miraculous

did it all again a year later. I've not been on any treatment since.

What impact did the treatment have?
I've won other tournaments. But winning the Jersey Seniors Classic in 2008 after I'd been diagnosed with MS was probably my most satisfying win. I'd been told I'd never play golf again at any decent level. To go out and win a tournament, thanks to the clinical trial, felt miraculous.

I've also loved doing the commentary for the last 20 years. I couldn't have done that without my memory. It's impacted my life hugely.

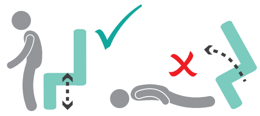
Why did you get involved with the MS Society?
I thought "I've been so lucky here." I'd had a wonderful break and I wanted to give something back. Research is vital and a lot of it wouldn't be done without the MS Society. And they give people with MS so much information and help. I wish I'd known about them when I was diagnosed.

I organised a golf day for the MS Society in 2009, which raised over £100,000. Since then, I've done other fundraising and awareness raising, including a bird photography challenge in South Africa. Being an MS Society Ambassador is a great honour.

Tony is raising funds for our Stop MS Appeal at a special event in June.

For more information email specialevents@mssociety.org.uk

Courtesy of Phil Inglis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“I know John is still helping people with MS

John Stanley, who died in March 2023, left a gift in his will to support MS research. He also donated his brain and spinal cord to the MS Society Tissue Bank. Kate, John’s wife, explains why he decided to support our future work to stop MS.

John was diagnosed with MS in 1992 when he was 45. Our son, Adam, was just three, and John’s diagnosis came as a big shock. But he faced it with resilience, often saying “Why not me?” instead of “Why me?”

His symptoms progressed very quickly and he retired on medical grounds in 1994. This dramatically changed family life for us. But despite all the challenges, we tried to make things as normal as possible.

John was determined to stay fit, diligently walking circuits of the house. He wanted to have some body function left if a cure or effective treatment was found that would help him. But his mobility continued

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to deteriorate. He went from one stick to two, to a walking frame, then a rollator and finally into a wheelchair.

John's mantra was "My body doesn't work, and my brain is buggered, but I'll keep going." He made me believe that having an MS diagnosis wasn't the end of family life. He'd say it's certainly a harder path to follow, but he was determined to make the best of everything.

Contributing to MS research

John participated in various MS trials, including a cannabis trial quite a long time ago.

He learned all he could about research into stopping MS. He was waiting in hope of a cure being found in time for him.

The Amersham and Chesham MS Society Group provided essential support, offering physiotherapy and yoga to keep John active. It was during a talk at the local group that we first heard of the MS Society Tissue Bank. As John was passionate about contributing to MS research, he signed to leave his brain and spinal cord to the Tissue Bank. His donor card went everywhere with him.

After John's death, the Tissue Bank wrote me a really lovely letter. They said "thank you" and explained that they take cells and samples from the tissue. These are then frozen and stored for years, ready to use. I know John's still helping other people with MS as he'll be part of the research going on. It's a wonderful feeling.

This has been a real comfort to the whole family and inspired me to become a donor myself. I learned the Tissue Bank wants brain and spinal cord tissue from people who don't have MS, to compare results. I feel so good knowing I too can be part of the work being done to stop MS.

John's legacy gift

John was very organised and we both wrote our wills early. John was clear that he wanted to include a gift to the MS Society to support future work to stop MS. When we updated our wills a few years ago, John decided to double his legacy gift to £10,000.

He'd love to know he's contributing to MS scientific research with both his body and money. He's now part of research to help develop treatments to help others.

We'd like to say a huge 'thank you' to John. His journey is marked by determination and resilience. And he leaves a lasting impact through his contribution to research, and the love of his family.

If you, like John, would like to leave a lasting gift to support our future work please email legacies@mssociety.org.uk, call us on 020 8438 0828 or visit mssociety.org.uk/legacies

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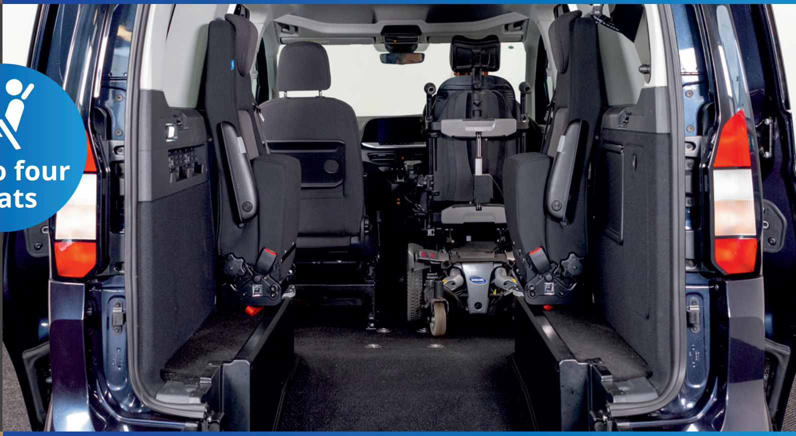

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FIVE THINGS YOU NEED TO KNOW ABOUT

The MS Society Tissue Bank

Our Tissue Bank allows people to donate their brain and spinal cord for MS research after their death. And these generous donations are helping scientists improve our understanding of MS – and find treatments to stop it.

1 Human tissue is vital for MS research

MS is a uniquely human condition. So to understand it fully, researchers use samples from the Tissue Bank to see how the condition affects the human brain and spinal cord. And testing potential targets for new drugs in human tissue is a critical step early in the drug development process.

2 Each brain and spinal cord donation becomes 250 individual samples

This means each donation can provide material to as many research projects as possible. A single donation can have a huge impact.

3 The Tissue Bank is based in London – but the samples are used in research all over the world

The Tissue Bank collects donations from across the UK. It's a truly international resource, supplying tissue to over 900 research groups across the world.

4 Research using the Tissue Bank has led to new treatments

Tissue Bank samples were used to study the role of B cells (a type of immune cell) in MS. Building on this work, scientists developed anti-B cell therapies like ocrelizumab (Ocrevus). This is used today to treat active relapsing remitting MS and early primary progressive MS.

5 You don't need to have MS to donate to the Tissue Bank

To understand what's happening in MS, researchers need to look at the differences between brain tissue from people living with MS and people without. So donations from people without a neurological condition are just as important.

The MS Society Tissue Bank is funded by donations. To support the Tissue Bank and other world-leading MS research visit mssociety.org.uk/research-give

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Ask the expert

Dr Stavros Vagionitis is a researcher at our Cambridge Centre for Myelin Repair. We asked Stavros about the impact of ageing on MS and his research into myelin repair.

Q How did you become interested in MS research?

I was lucky to join a lab working on myelin research during my PhD in neurobiology in Germany. At first, I was driven by scientific curiosity. But I do have a family member affected by MS. And I've met many people with MS through my work, so I've seen its impact first hand.

Q Does MS typically change as people age?

MS affects younger people as well as older. This makes it different from many other serious neurodegenerative diseases. And MS affects each person differently. In general, younger people are more likely to experience relapsing remitting MS. This is when people have relapses (where symptoms get worse) followed by periods of recovery. As people with MS get older, many begin to experience progressive forms of MS with more advanced and consistent disability.

We now have therapies for relapsing remitting MS and some emerging for progressive MS. But more work needs to be done to find effective treatments for everyone. Especially for older people who have accumulated more disability over time.

Q How does the immune system change with age and how does this affect MS?

This is an active area of research in our lab. The immune system attacks the protective myelin coating around nerves by mistake in MS. So far, we know that microglia, the brain's immune cells, seem to be more active in an ageing brain.

We're investigating how this could affect the delicate balance of inflammation in the brain. And how it might affect myelin repair.

Q How does ageing affect myelin repair?

Our brains can repair myelin using cells called oligodendrocytes. These cells are damaged or destroyed in MS, but the body can make new ones. Cells called oligodendrocyte precursor cells (OPCs) divide and turn into oligodendrocytes. These can then repair the myelin. This process usually works well in younger people and happens during the remitting phase of relapsing remitting MS. But it stops working so well with age. So damaged myelin is less likely to be repaired. This leaves nerves vulnerable to damage – and they may be lost over time. This contributes to MS progression.

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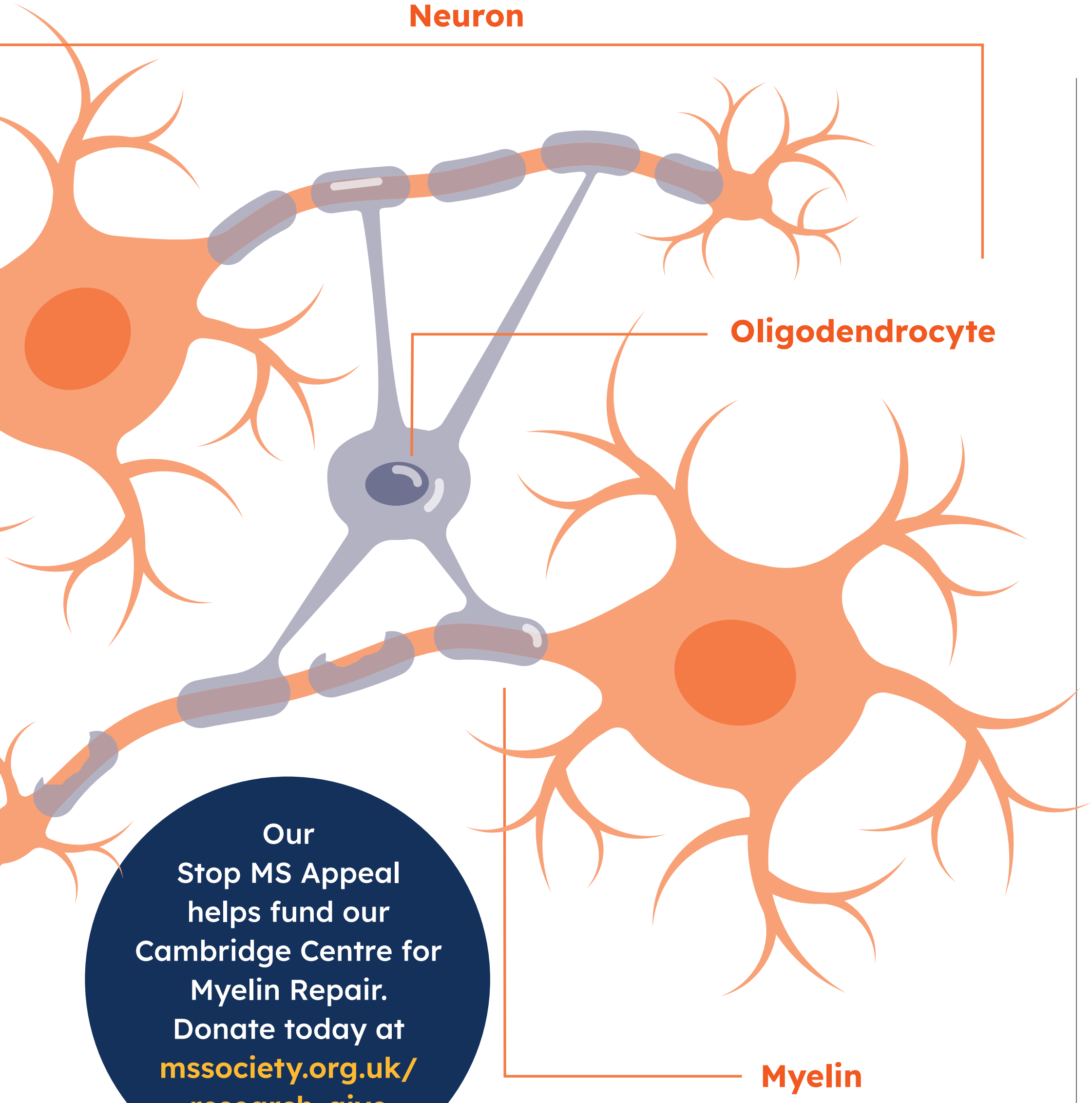

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MEET THE EXPERT

Dr Stavros Vagionitis

Q What does your research focus on?

At the Cambridge Centre, we bring together basic research and clinical trials. This allows us to quickly turn lab findings into potential therapies.

My project focuses on how ageing affects myelin repair. I create brain lesions using mouse and rat models. And then I see how they're repaired. I look at how this changes with age. I want to understand why OPCs fail to repair damage with age. Do they fail to turn into oligodendrocytes? Or do the problems happen later when they're making myelin?

Not all OPCs are the same. My goal is to identify the specific OPCs most effective at repairing myelin. And to see if we can encourage less effective OPCs to behave more like these 'younger', more effective cells. To achieve this, I'm studying which genes are switched on in the most effective OPCs. And I'm developing methods to track these cells and their activity.

I hope to find ways to rejuvenate OPCs and restore their ability to repair myelin.

Q What could this work mean for people with MS?

We hope a combination of promoting myelin repair with other disease modifying treatments targeting the immune system could help stop MS progression and improve people's quality of life.

FIND OUT MORE ABOUT... THE CENTRE

Read about our Cambridge Centre for Myelin Repair at mssociety.org.uk/cambridge-centre

My fundraising challenge

Our Stop MS Appeal is a team effort! We're so thankful to everyone in the MS community taking on fundraising challenges for MS research. Here are just a few of your stories.

Walking the length of England

Tom Mercer walked from Berwick-upon-Tweed to Land's End, raising £26,698 for MS research. He completed the walk in September 2023 covering 736 miles over 29 days with five rest days.

Tom, aged 46, was diagnosed with relapsing remitting MS in 2010. Since then, he's tried several treatments and now takes Kesimpta (ofatumumab).

Tom says "I was starting to have walking difficulty before Kesimpta. And I certainly wouldn't be doing what I am now without it.

"I'm lucky I was physically able to do this challenge. I had lots of time to think and listen and enjoy the scenery. I used it to raise money and also awareness as I met people along the way and had discussions about MS. A diagnosis can be really scary. I hope talking about it can help in some small way.

"I'm pleased I can use my MS to do something positive to raise money. Since I've been diagnosed, treatments have come on so much. To see that change has inspired me to want to raise funds for this research and the Stop MS Appeal."

Whether you're taking part in one of our events or want to do something different, our website is full of tips and ideas. Visit mssociety.org.uk/fundraising-ideas

My MS Woof: no dog, no problem!

Tricia Cable raised £777 for MS research by taking part in My MS Woof in October 2024. Tricia, who has MS, broke her hip a year earlier. She wanted to challenge herself to walk further every day once she'd recovered.

Tricia says "I don't have a dog, but I love walking with dogs. I'm part of a walking group mainly made up of dog owners. I decided part of my challenge would be to walk with as many different dogs as possible. The support I had from the group was heartwarming.

"My MS Woof increased my confidence, motivation and hope I can keep walking in beautiful countryside.

"I want to contribute to research to find effective ways of managing and treating MS. I'm encouraged by research looking at the gut microbiome and other ways to support our health and wellbeing."

If you're a dog lover like Tricia you can register your interest in My MS Woof in 2025 on our website mssociety.org.uk/ms-woof-25

Driving change for MS research

In a heartwarming display of community spirit, the Grove Golf Club in Porthcawl raised £7,263 for the MS Society in 2024. Led by Captain William Hanford, the club surpassed its initial goal of £6,000, after choosing us as their 'Charity of the Year'.

For Will Hanford, the cause is deeply personal. He says "When I was made Captain of the Grove Golf Club, there was no question about which charity I would choose. My wife, Christine, has lived with MS for 30 years. I wanted to do all I could to help stop MS."

With support from the club's members, the year was filled with events that brought the community together. Highlights included the Captain's Charity Golf Day, four quiz nights, a charity fashion show and tea, and a thrilling race night.

"We're absolutely delighted to have exceeded our target," said Will. "The generosity and support from our members and community have been incredible and the funds will contribute to critical MS research."

If you're a golf lover like Will, why not get your club involved? To find out more visit mssociety.org.uk/golf-days

Tell your true story with bravery

Sameerah took part in our MS Walk in Birmingham in 2024 after being diagnosed with relapsing remitting MS in June 2023.

She says "I started a disease modifying therapy (DMT) called Ocrevus (ocrelizumab). My MRI revealed I have over 20 lesions in my brain and one in my cervical spine. Hopefully, I won't have more lesions on the next scan!

"I'm so fortunate to be able to walk, talk, see, swallow, think and just generally function as normal. There are so many people with MS who struggle with symptoms every single day. Despite medications being available for some people to hopefully slow the progression of MS and reduce relapses, further research is needed."

"I raised £4,065 by doing the MS Walk. I'd advise anyone looking to fundraise to be open and tell their true story with bravery and honesty. Reach out to friends and family, speak with colleagues and don't be afraid to bring awareness to the cause."

To find out about joining an MS Walk in 2025, turn to page 10 or visit mssociety.org.uk/ms-walk-25

Five fundraising tips

1 Set up an online fundraising page

This is a quick and easy way to increase the amount you raise. Visit our section on the JustGiving website at **justgiving.com/mssociety**

2 Get sponsored

We can also give you paper sponsorship forms to put up at your work or community space. Keep some with you all the time!

3 Get your employer involved

Many companies will be happy to offer a donation or even match the money you raise. Your work is also a great place to run fundraising events like a Cake Break or raffle.

4 Make more with Gift Aid

Ask your sponsors/donors to Gift Aid their contribution. This means you'll add 25p per £1 onto your fundraised amount at no cost to you or your sponsor/donor. Find out more at **mssociety.org.uk/gift-aid**

5 Tell the world

Share your fundraising on your social media and in person. Tell colleagues, family, friends and people from your local school, community or religious centre.

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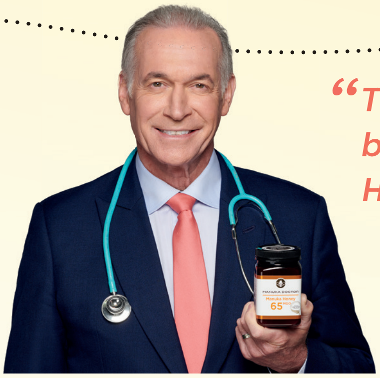

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Dr Hilary Jones
Media GP

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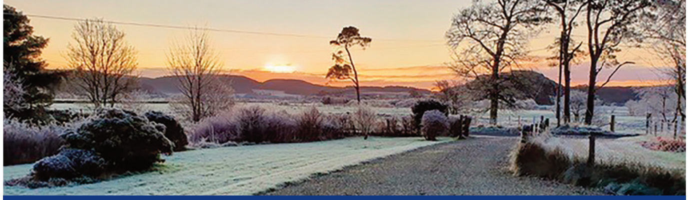


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Have your say

We asked what topics you'd cover if you were the MS Matters editor. Here are some of your amazing ideas. Look out for them in future issues.

I'd cover acceptance. I'm grieving the loss of the life I was hoping to live with my symptoms. It's been so hard for me to accept new limitations and things like needing a walking aid. I'm still working on being okay with the fact I've got to do things a bit differently.
chloeanne211

Loss of functioning while speaking. It wipes me out just trying to get a sentence together, never mind getting it out of my mouth. The words get lost mid-way. How do you explain this to people? It drives me insane. It's so stressful. I have so much to say but not enough patient ears to take the time to listen.
Ελενι μαριε

I'd like to see MS in old age covered. I'm 75 years old and was diagnosed on 11 November 2024 after being diagnosed with other things or ignored for 40-plus years. How does it change life and impact mental awareness?
Mary Rosanne Smith

I'd talk about the opportunities you can create following a diagnosis which you might never have thought of before illness.
yorkshiremslass

Coping with the huge mental health impact of being newly diagnosed. Having zero idea how it will progress and what the future holds.
Anna-Louise Moss

Dealing with neuropathic pain.
Trish Richards

Self-esteem and mental health, like managing unnecessary guilt for things we can't control.
Natasha Perkins

How to approach children and grandchildren about why you can't do things. I'd like to see an article aimed at children so they can understand.
Mimsey Sue

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FOR OUR NEXT ISSUE WE'RE ASKING…

What local support or service has had a positive impact on your daily life with MS?

Send your thoughts to **msmatters@mssociety.org.uk**
We'll also post the question on our social media at **facebook.com/mssocietyuk** and **instagram.com/mssocietyuk**


NEW
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73.6

Your thoughts

Melissa Smith, who was diagnosed with relapsing remitting MS in 2007, shares how embracing creativity helps her manage her symptoms.

I read with interest the article titled The Creativity Factor (Autumn/Winter 2024 issue, page 18).

As a child, I'd always enjoyed art and making things. I've done dressmaking, pattern design, upholstery, tapestry and flower arranging. In 1996, I attended evening classes to learn how to paint with watercolours. Then other demands took over and I shelved my artistic pursuits.

I took up watercolour painting again and joined a local art group three years ago. It's provided an opportunity to explore my creativity with like-minded people who don't judge and are highly supportive and inspiring. I enjoy painting flowers from observation and photos.

My MS symptoms vary but include constant extreme fatigue and a loss of feeling in my left leg and hand. I've also had optic neuritis, Lhermitte's sign (an electric shock when bending my head forward) and trigeminal neuralgia (facial pain).

How painting helps

Painting helps me manage these symptoms by allowing me to focus on what I can do. My awareness of my symptoms fades because I'm absorbed in the moment. I feel calm, tranquil and relaxed. Overall, it's extremely therapeutic for the mind.

Painting on my own is restful. But being with other members of the group adds another dimension. There's laughter, appreciation of others and the opportunity to share ideas. It's about being part of a community and feeling a sense of belonging.

The benefits continue long after the class. I feel positive and have a greater sense of worth and achievement. And I have a fabulous night's sleep!

DO YOU HAVE SOMETHING TO SHARE?

Please get in touch and let us know your views.

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Volunteer spotlight

“Our son set us the challenge of raising £1 million”

Yvonne Booth and her husband Duncan, who lives with progressive MS, organise the 10in10 annual fell walking challenge in the Lake District. Yvonne shares the inspiration for the challenge and their hopes for the future.

Since 2011 Yvonne and Duncan have raised over £840,000 for the MS Society, with £75,000 going to the Cambridge Centre for Myelin Repair in 2024.

Yvonne says “My amazing husband Duncan is the inspiration for 10in10 and the reason we keep going year after year. Duncan was one of Britain’s best rock climbers before his MS diagnosis in 2010. We set up 10in10 in 2011 because we wanted to create an event that incorporated something so important to Duncan.

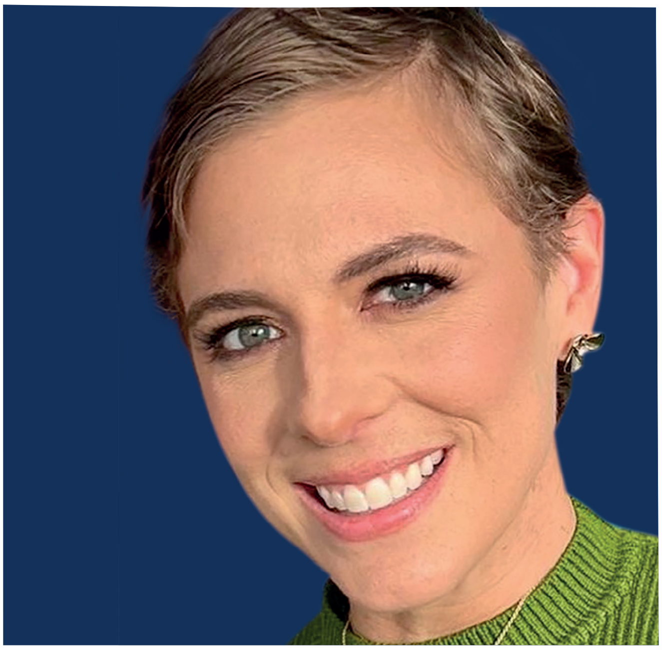
“We’re people of the fells. We’ve lived and breathed the Lake District all our lives. We wanted other people to experience the beauty of the area while also raising lots of money for the MS Society. Each year the success of the event surpasses all our expectations. Not only with the number of people who want to do it but also the amount of money raised.

Positive and hopeful

“Our children were very young when we started the challenge. But they’ve grown up seeing the time and passion we’ve put into it. We’ve always stayed positive and hopeful for the children’s sake and wanted them to grow up in a happy home. Dunc’s determination and humour have taught them valuable lessons about life and how resilience and laughter are so important. Now they’re older they understand how incredibly difficult MS is for their dad. I’m so proud of how they’ve got involved in organising the challenge as they’ve grown older.

“One of our sons, Xander, set us the challenge of raising £1 million when we first started 10in10. We’re so close to reaching that goal now. We’re already planning a huge party to celebrate the milestone. But 10in10 will probably carry on for many years to come. It’s such a huge part of our life and we want to stop MS once and for all.”

Do you want to join Yvonne and Duncan for this year’s 10in10 or the family-friendly 5in5? Find out more about these events at mssociety.org.uk/10-in-10



Getting to know you

Elizabeth Seigler

Elizabeth joined our Stop MS Appeal Board in November 2023. Together with the other Board members, she's helping drive our fundraising ambitions to reach our £100 million target.

What motivated you to join the Stop MS Appeal Board?

I was diagnosed with MS in 2012. At first, I was a bit in denial. I didn't have that many symptoms. And I was having my children, now aged 13, 11 and nine. As I started to experience increasing disability, I began to acknowledge how much MS impacts people.

I was recovering from a stem cell transplant and I wanted to direct my energy in a positive and hopeful way. Then my husband got to know David Silver, another Stop MS Appeal Board member. David encouraged me to get involved.

Tell us about your role with the Board

My role is to help with fundraising. People and companies have been so generous. I think of my role as trying to get some new people involved, as well as spreading awareness about MS and the research that's being done.

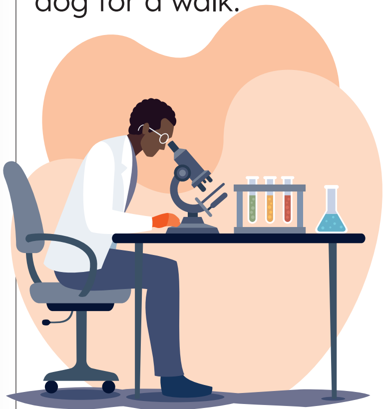
What are you most excited about when it comes to the research?

I'm excited about the projects on repairing myelin (the protective coating around nerves that gets damaged in MS). I think this is going to be a game changer for so many people. And it could apply not just to MS but also to other neurological conditions.

Looking for the cause of MS is also interesting. Finding ways to figure out who's at high risk and looking at ways to prevent MS.

What gets you out of bed in the morning?

My children, to be honest. But I also have a huge amount of optimism. My disability has been quite difficult for the past three years. I'm in a wheelchair when I'm outside of my house, so that's been a huge adjustment. What gets me out of bed is the motivation to keep working hard at my physio. I want to do the school run again. And take my dog for a walk.



What makes you hopeful?

Working on the Stop MS Appeal makes me super hopeful. Seeing all the brilliant scientists and researchers who've dedicated themselves to finding solutions to MS. It's so heartening to see.

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