

Winter 2023

MS Society

your Advances

thanks to you!



Your support,
your impact

Inside

- #BreakingPoint campaign
- 70 years of the MS Society
- Our Impact Award winners
- Research update

Welcome to your Advances

Happy New Year! Welcome to the first edition of your Advances for 2023.

2023 marks an impressive milestone for us. In December it will be 70 years since our founders hosted the first ever MS Society meeting. So much has been achieved to help the lives of people with MS since then. And it's thanks to supporters like you.

We know 2022 was a challenging year for people across the UK. But with your support, we've been able to continue supporting the MS community. Inside we look at how the cost of living crisis continues to affect people with MS. And how we're appealing to the UK Government for more support.

You can also read about our benefits advice service and how it's supported Sasha and her family plus more updates and news about the difference your support is making.

With warmest wishes for 2023,

Nick Moberly,
Chief Executive



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0300 500 8084

(Monday to Friday, 9am to 5pm)



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**FUNDRAISING
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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)

We have an exciting year of events scheduled for 2023.

From our Annual Lecture, MS Awareness Week to runs, walks and cycles there's something for everyone. Pencil us in!

Dates for your diary

-  **1-28 February** My MS Walk
-  **2 April** London Landmarks Half Marathon and Brighton Marathon
-  **23 April** London Marathon
-  **24-30 April** MS Awareness Week
-  **30 April** Belfast Marathon
-  **13 May** MS Walk Manchester
-  **20 May** MS Walk Bristol
-  **25 May** Annual MS Society Lecture (register your interest with specialerevents@mssociety.org.uk)
-  **28 May** RideLondon-Essex 100
-  **28 May** Edinburgh Marathon Festival
-  **28 May** The Big Leap
-  **17 June** 10 in 10 or Family 5 in 5 Challenge (visit www.10in10.org.uk to sign up)
-  **10 September** Great North Run



Walk, roll, or stroll at one of our MS Walks in either Bristol or Manchester this spring, or set your own challenge for the month of February.



Or, if you're really feeling adventurous, celebrate World MS Day by skydiving from up to 10,000 feet!

For more information on the above events and to sign up, please visit mssociety.org.uk/fundraising

The cost of living crisis and MS



This is a tough time for everyone. But many people with MS are making devastating choices between essentials like food, heating and medication.



Nearly 2 in 5 people with MS claiming means-tested benefits can't afford to keep their homes warm. And around a third of this group can't afford the medication or treatments they need



Around 3 in 10 people with MS have had to reduce their spending by reducing or stopping therapies or treatments



Nearly a third of people with MS sometimes or often can't afford to eat balanced meals

What are we doing about it?

People with MS are being hit especially hard by the cost of living crisis. So we launched our #BreakingPoint campaign in October to call on the UK Government to recognise that and take real action to support the MS community.


What has happened so far?

We saw some real wins in the UK Government's Autumn Statement in November. They announced benefits will increase in line with inflation from April. And there'll be new cost of living payments this year.

This was a great start. But many people with MS have faced a long bleak winter and can't wait until April.

What's next

We haven't finished campaigning on the cost of living crisis or disability benefits. Join our campaigns community to keep up to date with the campaign as it progresses at mssociety.org.uk/join-campaigns



We handed in our petition with 14,366 signatures to Downing Street at the end of last year. Our petition called for the UK Government to:

- urgently introduce an additional cost of living support package for disabled people before the end of the year
- increase benefit rates to fully cover the extra costs of living with MS
- pause debt repayments for people on benefits.

“I’ve already stopped activities for my son and me, including our swimming. We were both learning to swim and beginning to enjoy it. I found it a good exercise to do for my MS, giving my whole body a workout.

I’m really worried about the next thing I’ll have to cut if costs go up any further. I need more support from the Government to help me through the energy crisis.”

Adeyinka

How has the cost of living crisis affected you? Share your story by emailing campaigns@mssociety.org.uk and help us put a face to the campaign.

MS Helpline, an update

If you followed our Autumn Appeal you'll know we got more calls to our Helpline than usual last year. And, thanks to everyone who donated, raised an incredible £49,000.

This means our volunteers and staff are still at the end of the phone, ready to offer expert advice and support to the MS community.

It's no surprise a large number of calls were from people in need of financial advice. Thankfully, we have a team of benefits advisors on hand to offer free advice to people like Sasha. Find out how the Helpline and benefits advice service helped Sasha in her MS journey on page 7.

“The MS Benefits Advice Service is in demand more than ever before. We saw requests for benefits advice increase dramatically last year. We gave 1,644 acts of assistance in 2022 compared to 1,053 the previous year.”

Darren, MS Society Benefits Advisor



If you have MS, or care for someone who has, you might be entitled to benefits, tax credits or other financial help. To find out more, speak to our MS Benefits Adviser by calling the Helpline on **0808 800 8000** or emailing **msbenefitsadvice@dls.org.uk**. The Helpline is open Monday to Friday, 9am to 7pm except bank holidays.



“ Thankfully, my PIP application was successful – it’s made a big difference. The money’s helped me get a house, pay bills, and get presents for my kids. ”

I’m Sasha, a mum of three living in Birmingham. I was diagnosed with highly active relapsing remitting MS in 2019 after my daughter was born.

The whole process to get diagnosed started while I was pregnant. I’d gone numb from the neck down, halfway through my pregnancy. I knew nothing about MS at the time. I just thought I’d keep getting worse.

In June 2019, I made my first call to the MS Helpline. I’d researched information about MS and found the Helpline’s details. In my first call I asked them what will happen to me and what my future might look like.

I now know they’re impossible questions to answer. But the woman on the phone was so lovely. She managed to make me feel much calmer about the future. And she told me about treatments, which reassured me.

In September 2019 I called again to ask about benefits because I was worried about providing for my daughter. I was connected to the Helpline’s benefits advice service and they helped me write my Personal Independence Payment (PIP) application. They even gave me guidance on what to say at the PIP medical assessment.

Thankfully, my PIP application was successful – it’s made a big difference. The money’s helped me get a house and pay the bills. I don’t think I’d have made it through that challenging time without the Helpline’s support.

It really made me feel like there was someone else that cared and could take the time to help me. Calling the MS Helpline made me realise you don’t have to be alone on your journey and there is support on every step of the way.

Celebrating our 70-year history...

1983

We give £1 million research grant for the purchase of the first magnetic resonance imaging (MRI) scanner in the world to be solely dedicated to MS research. The scanner changed the way MS was diagnosed.

1973

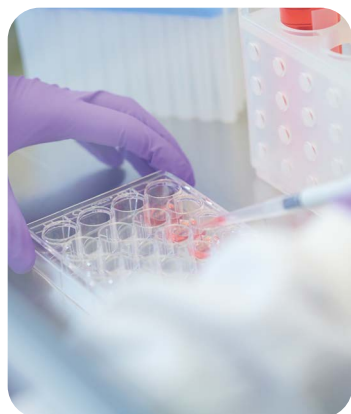
Our research spending reaches £1,000,000.

Late 1990s

The first disease modifying therapies (DMTs) become available for some people on the NHS. They're licensed for relapsing remitting MS and some people with secondary progressive MS with relapses. There have since been over a dozen more DMTs, including the first for some people with primary progressive MS.

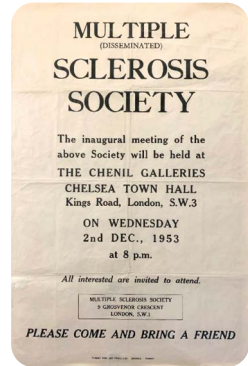
1991

We launch our MS Society Helpline. Alongside local groups – then called branches – the MS Helpline gave people more ways to find support and information.



1953

In 1953, our founders Richard and Mary Cave were frustrated at the lack of treatments and support available for Mary's MS. So they decided to do something about it. They set up their first meeting in West London, a small number of people came and the MS Society was born. Richard and Mary's work has inspired thousands of volunteers, supporters and staff members to make a difference to the lives of people affected by MS.



1962

Our 'Welfare Services Spending' reaches £63,000 to help support and care for people affected by MS.

1958

We establish the Research Fellowship Scheme, our first funding programme for scientists doing MS research.



2005

The Cambridge Centre for Myelin Repair is set up, followed in 2007 by the MS Society Edinburgh Centre for MS Research. We still support both with grants. An important part of their work is advancing research to slow and stop MS progression.

2022

Turn over to read some highlights from 2022

Want to read the full timeline history?

A more detailed version of the timeline was published in our recent MS Matters magazines. You can get future copies of MS Matters delivered to your door by subscribing for just £5 a year. Visit www.mssociety.org.uk/msmatters. Or call our Supporter Care team on **0300 500 8084**.

2022 highlights

- **Our MS Helpline answered over 28,000 enquiries**, combatting isolation and offering emotional and practical support to the MS community.
- **Our 242 local groups continued to meet in person** and virtually to give friendship, support and information about MS.
- **We awarded around £2 million worth of new funding** to research projects, bringing us one step closer to stopping MS once and for all.
- **We've continued to campaign** and speak up, fighting for the MS community to have the treatments, services, care and support they need.

But none of this would be possible without your support – thank you!

2022 Impact Awards

In October last year, we held our first Volunteer Impact Awards event. Hosted by Scott Mills, the event celebrated the impact our volunteers make and recognised outstanding individual contributions. It is our pleasure to introduce the finalists and winners.

Informing

Winner:

Charlotte Hecht



Charlotte shares her lived experience to raise awareness of MS.

Finalists: Carla Callaghan, Kirsty Bennett

Influencing

Winner:

Simon Hoare MP



Simon continually supports our campaigns and raises the profile of MS in Parliament.

Finalists: Amy Sutherland, Lynne Roberts

Sharing Skills and Expertise

Winner:

Robert Oldham



Robert uses his HR background to inform others about employment issues and MS.

Finalists: Lorraine Russell, The Self-management Co-production Team for MS Society Wales (Amanda, Hayley Driscoll, Lynne Madden, Eirlys Ryder, Nikki Flynn, Paul Saurin, Sharon Hier, Valerie Simmons).

Connecting Winner:

The award went to Thomas Sykes who sadly died unexpectedly in February earlier this year. The award was accepted on Tom's behalf by his nephew, Ash.



Thomas played a huge part in bringing the MS community in Mansfield together.

Finalists: Fiona Salamone, Vicki Brice

Fundraising

Winner:

Gareth Reynolds



Gareth raised over £70,000 through a 3000-mile solo row across the Atlantic.

Finalists: Liam Waddington, Mary's Snowflake Creations (Catherine and Chris Heaton and Winnie Barrett)

Supporting and Empowering

presented by Tom Kerridge

Winners: Chris and Anne Todd



Anne and Chris hosted online events during the pandemic to prevent isolation.

Finalists: Louise Nicholas, Claire Wakefield

You can watch the 2022 Impact Awards and find more information about how to nominate someone on our website here: mssociety.org.uk/volunteer-impact-awards

Feeling inspired?

If reading these stories has inspired you to get involved please take a look at our latest volunteering vacancies: mssociety.org.uk/volunteering

Following the Trial Trail



An update on StarMS trial...

StarMS is an NIHR-funded trial of HSCT (haematopoietic stem cell transplantation). It's comparing the safety and effectiveness of HSCT with four other disease modifying therapies (DMTs). Recruitment opened in Sheffield earlier this year. And they're now enrolling people with MS at hospitals in London, Southampton and Nottingham too, with other sites around the country opening soon.

Why is this trial needed?

Dr Sarah Rawlings, our Executive Director of Research & External Affairs, said: "HSCT can be life-changing and some people with multiple sclerosis see their symptoms stabilise or even improve after receiving it. We currently don't know enough about the benefits or safety of HSCT compared to other DMTs that're also highly effective. But, like HSCT, they can come

with serious side-effects. "The evidence from StarMS will give vital information for people considering treatment options. At the moment, NHS eligibility criteria are strict and availability in the UK is limited.

The trial itself should help a larger number of people with MS get HSCT. And in the longer term, knowing how the treatment compares to other very effective treatments could give clinicians extra confidence to recommend it. It could also convince the NHS to make it more widely available across the UK. That would make it easier for people who could benefit to get treatment."



Find out more and take the eligibility questionnaire

Our research is made possible by incredible supporters like you. Your help has funded MS research since 1956. And in that time we've invested £227 million (in today's money) in research. This makes us the biggest charitable funder of MS research in the UK.

Octopus trial one step closer to launch...

Octopus is a new clinical trial for primary and secondary progressive MS. After some delays, it's now had the official thumbs up from the regulators. This important milestone brings us another step closer to the trial getting started. Its goal is to find treatments that slow or stop disability worsening. And its unique design means we can test potential treatments more efficiently.

When will we know the results?

We won't know if these drugs slow disability progression until 2028 at the earliest. This is because Octopus is combining

what would normally be two separate trials into one. So in the meantime, we'll be watching out for the results of other exciting trials for progressive MS, including:

- Professor Chataway's MS-STAT2 trial
- The ChariotMS trial
- The drug company Sanofi's trials of a new drug called tolebrutinib

These results are all expected by the end of 2025, thanks to the many wonderful people taking part over many years.

How can people with MS take part in Octopus?

The team is hoping to recruit at least 1200 people with progressive MS to take part in Octopus. People will join the trial gradually over the next six years. So there'll be lots of opportunity to get involved.

University College London Hospital were the first site to start participants late last year. And there'll be sites opening around the UK, including in Scotland, Wales, Yorkshire, the West Midlands and Hampshire.

If you're interested in taking part in this or other clinical trials, talk to your MS team. You can also register your interest in Octopus through the UK MS Register at

www.ukmsregister.org

Fundraising across the UK

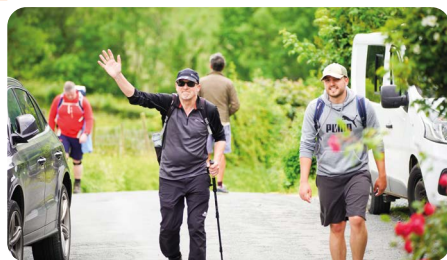
Fundraisers like you have been doing wonderful things all year. And we wanted to say a huge ‘thank you’ to the...

188 who took the big leap and skydived at 10,000 and raised £155,000

400 who took on the Lake District peaks at the 10 in 10 or 5 in 5 challenge and raised £71,000

137 who trekked and raised £166,863

280 who completed the London Marathon and raised £554,232, and the 60 who took on the Berlin Marathon and raised £53,639



52 who overcame obstacles at muddy runs and raised £33,670

28 who summited Ben Nevis by night and raised £15,979

88 who completed a Kiltwalk and raised £54,671

985 who walked, rolled or strolled at MS Walks all over the country, or completed their own one and raised £202,000

533 who did their own thing and organised a fundraiser for the MS Society and raised £671,348

Thank you to the hundreds of incredible MS Superstars across the country who've fundraised this year. Whatever you chose to do, you're bringing us closer to our vision – a world free from the effects of MS. You are amazing!

148

who cycled and raised £80,000

819

who ran in other events, from 5ks to full marathons and raised £366,405!

182 whose pawsome pups took on the My MS Woof challenge in October and raised £44,000

Thank you to anyone who donated in memory of a loved one this year. You raised an amazing £343,000 in honour of people no longer with us.

And a special **thank you to...**

In 2022, Gary Rushworth walked from Land's End to John O'Groats and across the length and breadth of the UK, all in 100 days. Gary took on his challenge in memory of his wife Moira, who lived with MS and sadly died in early 2020. Gary raised over £10,000 for Octopus to help stop other people going through the same challenges as Moira and their family and friends. Gary's local group, the Furness Group, were so inspired by Gary that they've also donated £7,500 in memory of Moira towards Octopus.





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 Sarah at 020 8827 0374
legacies@mssociety.org.uk or visit
mssociety.org.uk/free-wills**