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motor neurone disease
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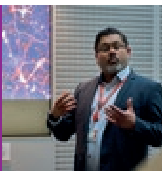
Membership

SPRING 2025

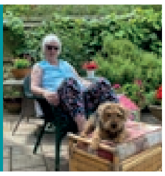
THUMBPRINT

NEWS FROM THE MND ASSOCIATION COMMUNITY

MP'S VISIT
King's College London
Page 9



YOUR GARDENS
Enjoying green spaces
Page 20



LEEDS MARATHON
Continuing Rob's legacy
Page 14

GROUNDBREAKING COLLABORATION

One-stop-shop sets new standards

Turn to page 7

SUPPORT | RESEARCH | FUNDRAISING | AWARENESS RAISING | CAMPAIGNING | VOLUNTEERING

CONTENTS

On the cover

Stephen Rees with MND Specialist Nurse Omina Yasmin at LOROS Hospice in Leicester.

Thumb Print is also available to read online, just scan the QR code or visit **mndassociation.org/thumbprint**

WELCOME
FROM OUR CHIEF EXECUTIVE TANYA CURRY

My garden is most definitely one of my happy places, particularly at this time of year, and I know that's true for many of you. Our outside spaces, whether that's a garden, yard or balcony, give us a sanctuary to relax in, a space to potter and a gathering place for family and friends. On pages 20 and 21 we showcase the gardens of three people with MND who find joy in their outside spaces. You can also learn about the grants we provide for adaptations to make your garden more accessible – whether that's replacing a rickety path or having raised beds built.

Our grants are just one of the ways we help people, and their families, following an MND diagnosis. Our *Impact Report 2024*, which we're sharing with this issue of *Thumb Print,* charts many more, from the support services we fund to the opportunities we're creating for people to take part in research. Do take a look to see how the incredible fundraising so many of you take part in is making a difference every single day.

Our determination to drive more impact is the key to our new strategy, which you can read about on page 12. We will be focusing on the three areas of work where we can make the most difference to people with MND now, and into the future: Tomorrow's Treatment; My Support My Way; Influencing High Quality Care.

We'll be sharing more about our strategy and the progress of our bold and ambitious plans at our Regional Roadshows. Following their success last year, this year we will be in Liverpool and Gloucester. You can sign up now to attend. And there's also more information on page 10 about our Annual General Meeting which you, as a member, are invited to.

There are lots more ways to get involved with our work – you will find QR codes throughout these pages which will link you directly from your tablet or mobile phone to information about our campaigning work, fundraising challenges and research.

That's just one of the changes in our new look *Thumb Print*. We wanted to introduce a brighter, bolder look with clearer signposting to further information and more of your stories. Do let us know what you think!

Tanya

> **"We'll be sharing more about our strategy and the progress of our bold and ambitious plans at our Regional Roadshows. Following their success last year, this year we will be in Liverpool and Gloucester."**
>
> Tanya Curry, Chief Executive

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If you have comments or feedback about the magazine and its content, please do not hesitate to get in touch.

SUPPORTING MULTIDISCIPLINARY TEAMS TO PROVIDE THE CARE EACH PERSON NEEDS

The MND Association's updated *Multidisciplinary Team Working for MND* guide provides practical advice and insights for delivering individualised care to people with MND.

The complex nature of MND means people require support from a wide range of healthcare professionals, including neurologists, nurses and social workers, as well as assistive technology experts and community care services. The MND Association's guide *Multidisciplinary Team Working for MND* is a vital resource, providing practical advice and insights to everyone involved in supporting people with MND.

The guide has now been updated in collaboration with health and social care professionals.

Erin Forker, Specialist Dietitian explains why collaboration between professionals is so important. Erin said: "As everyone is aware of the advice given and what was discussed, the person with MND is not asked the same questions over and over again and they can leave the assessments with a lot more information. People with MND get the care of a team working towards the same goal, who knows what they may need and want."

International guidelines, such as those from the National Institute for Health and Care Excellence (NICE), strongly recommend MDTs. Our revised guide is designed to support professionals in meeting NICE recommendations and covers everything from the benefits of an MDT to practical tips for setting up and maintaining an effective team. It also includes real-world examples of challenges faced by health and social care professionals and practical solutions to address them.

Studies have shown that this kind of integrated care improves both quality of life and survival rates for people with MND. It facilitates their access to timely interventions, assistive services, and even clinical trials. It also enables them to have points of contact with people they can ask for support.

Keri Vickery, MND Care Centre Co-ordinator is the key point of contact for people with MND in her area. Keri said: "My colleagues from many different disciplines each play such a crucial role in addressing the multiple, complex issues

> **"Try and build up a relationship with your professionals, especially if you see a multidisciplinary team (MDT). I really like my gang and enjoy seeing them, so my appointments aren't intimidating now… more like a social event."**
>
> Sue Vale, living with MND

The MDT sessions benefit both patient and professionals involved, to better understand and tailor care to their needs and preferences

that can be experienced by people living with MND. I'm a huge believer that the whole becomes more than the sum of its parts when the MDT works well together. I try to invest time in developing relationships within and across services to benefit our patients."

An effective MDT offers benefits not just for people with MND, but also for the professionals involved in their care. It allows team members to have a better understanding of the needs and preferences of a person with MND and of other professionals' decisions, ensuring everyone is aligned in their care approach. It also creates space for professionals to collaborate, share ideas and offer emotional support.

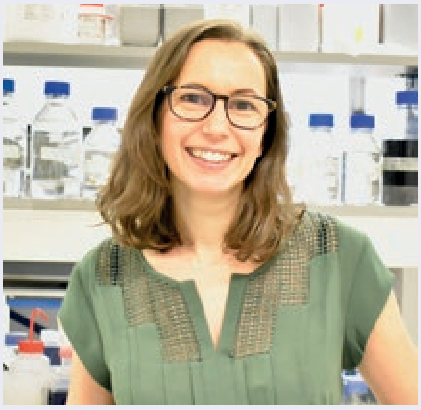
Emma Moore, Specialist Physiotherapist said: "For us professionals, it's beneficial to meet and link with all those different services that you might not come across at other times, but with whom you can discuss and exchange advice. It's useful to share information, solve problems with the help of others and learn from each other, while keeping the person with MND at the centre of care."

To support the creation of more MDTs, the MND Association offers a range of services from auditing current care services and helping build a business case for establishing an MDT, to offering training opportunities in MND care and facilitating our Community of Practice - a space for professionals to network and share knowledge.

To learn more and see the full guide, visit our brand-new webpage on MDT working: www.mndassociation.org/mdt or order printed copies from our MND Connect helpline: 0808 802 6262 mndconnect@mndassociation.org

MEET THE RESEARCHER - DR REBECCA SALEEB

Dr Rebecca Saleeb is searching for proteins only present in people with MND. These biomarkers act as 'flags' of disease and could be used to develop a simple diagnostic test, such as a blood test. She's studying molecules we already know are involved in MND such as TDP-43 but also wants to understand why several proteins build up simultaneously in neurodegenerative conditions. Here, Dr Saleeb tells us more.



Dr Rebecca Saleeb is a Research Fellow at the University of Edinburgh and was awarded the MND Association's Lady Edith Wolfson Non-Clinical Research Fellowship in 2023 to support her work looking for new ways to diagnose MND earlier. Getting a diagnosis means people can access support and treatments more quickly and join clinical trials sooner. Currently, diagnosis can take months and involves many tests, hospital visits and much uncertainty.

My expertise is actually in microscopes. But I've always wanted my research to be impactful, and there is nothing more impactful than working on MND. It's an aggressive, incurable disease, and I want to dedicate my work towards something where we can really make a change.

There are some exciting things going on in diagnostics. Some recent work in biopsies has suggested indicators that show signs of MND can be present 10 years before symptoms begin.

A typical day

I get in early to take advantage of the quiet time to plan experimental details, analyse data or write up results. After that I'm usually jumping back and forth between the lab and other jobs, like meetings to support students, discussing data, attending seminars or catching up on reading. I almost always have a timer running to keep me on track in the lab.

MND Association funding

I'm funded as a Junior Research Fellow by the MND Association. This has enabled me to work towards developing new or early-stage diagnostics so that we can speed up the diagnostic process. This would enable people with MND to access drugs earlier when they could be at their most effective. The work the MND Association does in funding our research is critical to me as a researcher. I'm also keenly aware this money was raised by the charity's supporters.

My research

My goal is to develop tools that allow us to detect MND early on using accessible human biofluid. Having a diagnostic test will help to speed up the time it takes for a diagnosis. I want to pull out biomarkers we already know, analyse them with fancy microscopes and use them to better understand what's going on inside the person.

HOSPICE-BASED MND CLINIC EXPANDS SUPPORT

Combining clinical care, mobility and support services reduces the stress of attending appointments at multiple venues

A monthly MND clinic has expanded to become a one-stop shop for people with MND, thanks to a groundbreaking collaboration that's setting a new standard in the delivery of care.

LOROS Hospice is collaborating with Opcare, a mobility services provider, to run a wheelchair clinic. Now, alongside meeting with their multidisciplinary care team including occupational therapists, speech and language therapists and dietitian, people with MND can also access wheelchair services.

And after their clinical appointments, people can then attend MND Association support group meetings, hosted by the Leicestershire and Rutland Branch. These meetings offer people with MND and their carers the opportunity to connect, share experiences, and chat to Association volunteers over coffee.

This new approach brings MND care and support together under one roof, as Scott Maloney, Service Development Manager at the MND Association explains: "We already know that LOROS offers gold-standard care to people living with MND in Leicestershire and Rutland. They were so open to Opcare's approach to run a wheelchair clinic at the hospice at the same time as the MND clinic and the branch's support group. I hope this co-ordinated model is something that can be replicated elsewhere."

This innovative approach makes it easier for people with MND by reducing the need to travel to multiple appointments at different locations.

Darren LeVay is living with MND and attends the sessions. He said: "Trying to get to different places for appointments is challenging. Having everything under one roof saves stress because my ability to get around now is reduced by my MND. It's a much more personal service and I am a name, not just another patient."

Claire Harrison, Clinical Lead Occupational Therapist at Opcare, was motivated by her previous experience supporting people with MND as a neuro occupational therapist. She saw how difficult it was for people to attend multiple appointments and approached LOROS with the idea of combining services.

Claire said: "When LOROS agreed to facilitate a clinic, we then looked at how we could provide equipment in a more timely manner. We organised for some powered chairs to be ready to prescribe so that we could respond quickly to people's needs. We also have a stock of manual posturally supportive chairs that can be issued on the same day."

Janet McMillan, Chair of the Leicestershire and Rutland Branch added: "Having the Opcare wheelchair team at our local MND clinic and support group meetings makes it so much easier for patients and carers. There's no need to make a separate journey to get help or advice."

By combining clinical care, mobility and the Association's support services, this collaborative approach sets a new benchmark for how MND services can be delivered to improve the quality of life for people living with MND.

> **"Trying to get to different places for appointments is challenging. Having everything under one roof saves stress because my ability to get around now is reduced by my MND."**
>
> Darren LeVay - who is living with MND

ED COOKE: OBITUARY

Trustee, Ed Cooke

MND Association trustee Ed Cooke sadly died in February, less than two years after his diagnosis of MND.

Ed, a member of the MND Association's Chiltern Branch, was elected to the Association's Board of Trustees in 2024, bringing his extensive skills as a lawyer and his personal experiences of living with MND to the role. He quickly proved himself a devoted trustee, who was well-liked and respected by all those who worked with him.

Ed's desire to support the MND Association started following his MND diagnosis, when he found the information and support offered invaluable. He wanted to give back to the charity and felt passionately about drawing on his own experience of the disease to offer first-hand insight into the journey of someone living with MND.

His passion shone through in everything he did for the Association. He was incredibly generous with his time and, alongside membership of the People, Culture and Inclusion Committee, and the Engagement and Income Generation Committee, he also dedicated time to a number of new and ongoing Association projects.

Usman Khan, Chair of the Board of Trustees, said: "Ed's contribution to the Board was significant. He was a unique individual and able to connect with the Association and his new colleagues immediately with remarkable warmth and openness. His contribution as a trustee was immediate and substantial and, while he was with us for such a cruelly short period, he has left his mark in so many ways. On behalf of all the trustees, we will deeply miss Ed and everything he brought to the role."

CHAIR'S MESSAGE

I start this message by acknowledging the sad news of the death from MND of our fellow trustee Ed Cooke in February.

In such a short space of time, by gifting us his expertise, time and energy Ed made a huge impact on so much of our work. My thoughts are with Ed's family and friends.

Of course we owe it to Ed, and to all the members of our MND community to continue to press forward, to push boundaries in our research, support and influencing work. And that's certainly our plan for 2025.

As I mentioned at the end of last year, this year we will be sharing our new strategy with you, setting out our goals for the next five years. I am always mindful when thinking ahead that our community doesn't have time to wait – we must work quickly but also with impact.

Your insight into what impact means for you is so valuable and we love to hear your ideas about what you want from your Association. We'll be heading out on the road again in the coming months for our second round of Roadshows, giving the Board and our Executive Leadership Team time to talk with you, listen to your ideas and discuss our thoughts. See page 13 for more information. You will also be able to register shortly for our AGM, taking place online on Wednesday 9 July. See page 10 for more information. As a valued member of our Association, attending the AGM means you can vote on resolutions that will shape the Association's future. I hope to see you there.

MPS TOUR WORLD-CLASS MND RESEARCH FACILITY

The MND Association welcomed members of the All-Party Parliament Group (APPG) on motor neurone disease behind the scenes at one of the country's leading research facilities to showcase the impact of its work.

King's College London invited five members of the APPG including Chair Ian Byrne, MP for Liverpool West Derby since 2019, to tour its laboratories at Maurice Wohl Clinical Neuroscience Institute in central London.

The day, organised by the MND Association in partnership with King's College London, included a talk from Professor Ammar Al-Chalabi, Director of King's MND Care and Research Centre and Co-director of the UK Motor Neurone Disease Research Institute (UK MND RI).

The presentation focused on the work of the Research Institute, a national network of six MND research centres collaborating to better understand MND and accelerate the search for a cure.

Ensuring the UK remains a world leader in MND research, removing the postcode lottery to accessing clinical trials, and encouraging investment into MND research were all on the agenda.

The second part of the day saw a tour of the state-of-the-art laboratory facilities, with the MPs hearing first hand from researchers about the innovative projects they are working on.

During the visit, Mr Byrne said: "It has been fascinating. Seeing people from across the world doing so much good in this facility shows just how much we need to continue funding research to cure this awful disease.

"It's been enlightening and inspiring for the Parliamentarians on the trip today to see where the money is being spent on key projects. A big thank you to everybody across the country who contributes to this important work."

Joining Mr Byrne for the visit were MPs Aphra Brandreth and Olly Glover, who are officers of the Group, and APPG Members Vikki Slade MP and Sarah Hall MP.

APPG Chair, Ian Byrne chats to a colleague during the visit

> **"Seeing people from across the world doing so much good in this facility shows just how much we need to continue funding research to cure this awful disease."**
>
> APPG Chair Ian Byrne, MP for Liverpool West Derby

Members of the APPG, Association staff with David Setters, who is living with MND, and his wife Helen

Afra Aabdien, PhD Student

BIOMARKERS IN MND

Getting a diagnosis of MND can take a long time because there is no simple diagnostic test. This can delay support being put in place and cause anxiety and uncertainty.

Researchers are working hard to find a test. To do so they need to identify biomarkers of the disease. Biomarkers are unique biological 'fingerprints' that signal the presence of disease. Finding biomarkers of MND could help clinicians to track the progression of someone's disease and help predict when they may need medical interventions, such as a feeding tube or ventilation support.

Biomarkers could also play an important role in testing new potential treatments. Some are already being used in clinical trials to see if drugs are working in the body to slow or even stop the disease.

The MND Association is currently funding 11 projects searching for biomarkers of MND. One of these, led by Dr Jenna Gregory at the University of Aberdeen, is using a new tool designed to stick to clumps of a toxic protein, called TDP-43. This protein is found in the affected cells in around 97% of people with MND.

The tool may help researchers to see where the toxic protein clumps occur in different areas of the brain.

Understanding more about the patterns of these TDP-43 clumps might lead to more personalised understanding of disease progression and earlier diagnosis of MND.

Researchers across the globe are committed to finding new biomarkers of MND to help accelerate diagnosis, provide more accurate information about disease progression and gain a clearer understanding of whether new potential treatments are effective.

Find out more about the biomarker research we fund on our website: www.mndassociation.org/research/our-research/research-we-fund/understanding-clinical-progression

INVITATION TO JOIN OUR ANNUAL GENERAL MEETING

Our Annual General Meeting (AGM) will be held online on Wednesday 9 July, giving as many members as possible the opportunity to attend.

The AGM is an opportunity to hear more about the work we do and ask questions of our Board of Trustees, our Chief Executive and the Executive Leadership Team. You will also be asked to play a key role in the governance of the Association by voting on matters of business, called resolutions.

The event will be hosted from our head office in Northampton. The agenda and joining details will be shared with you over the coming weeks.

You can register to attend the AGM via this link https://mnd.eventsair.com/annual-general-meeting-2025/agm25

COULD YOU BE A TRUSTEE?

Closing date for applications

14 MAY 2025

We are currently looking for a new elected trustee to join our Board of Trustees.

Members will vote for candidates in Trustee Elections held in June hosted by our election provider Civica with the newly elected trustee being announced at the AGM on 9 July.

Trustees are volunteers with legal responsibility for overseeing the Association. They act together to govern the Association where they help to set its strategic direction. Trustees are responsible for making sure the goals of the MND Association are met, ensuring it continues to meet the needs of people living with and affected by MND.

So, if you feel as passionately about our work as we do, and would like to become part of our growing charity, you can find more information about the role and how to apply online at **https://www.mndassociation.org/trustee-elections-2025**

"YOGA HELPS ME LISTEN TO MY BODY"

Many people living with MND use therapies and exercises to ease their symptoms and enhance their wellbeing. While these can't reverse the progress of MND or Kennedy's disease, when used alongside medical treatments, they can provide a holistic approach to symptom management.

Complementary therapies like aromatherapy and Reiki can help to reduce anxiety and improve mood. Rick Nelms has regular aromatherapy sessions with essentials oils to help manage his MND symptoms. Rick said: "Aromatherapy is pleasant and relaxing. I find it helpful in pain management."

Since her diagnosis of MND, Sue Vale uses conductive education therapy to help her movement and mobility. Sue said: "Conductive education therapy has increased my confidence and made me aware that timely precision is more important than speed. It is demanding physically and mentally, but it is so useful as it gives me strategies to help mobility and stability."

For some people with MND and Kennedy's disease, exercise can be beneficial. Tim Harris-Jukes, who lives with MND, attends hydrotherapy exercise sessions run by a team of physiotherapists and occupational therapists.

Tim said: "We do exercises to improve balance, and resistance exercises with various floats to improve muscle strength.

"These sessions also provide a social aspect as I am able to connect with the healthcare professionals who run the sessions. I also recommend yoga to everyone living with MND. Yoga helps me listen to my body and provides solutions to ease aches and pains."

Many complementary therapies are available through the NHS or local hospices. Whether seeking complementary therapy or starting an exercise programme, ask your GP for referral to a qualified practitioner or physiotherapist. They can assess your needs and tailor any routine so that it is right for you.

Some of the most common complementary therapies include:

Acupuncture: fine needles are inserted into your skin at specific points, thought to be lines of energy.

Aromatherapy: essential oils from plants are used to support your physical, emotional and spiritual wellbeing.

Massage: the rubbing and kneading of muscles and joints to relieve tension or pain.

Meditation: focusing or clearing your mind using mental and physical techniques.

Reiki: it is thought that a therapist can channel energy by means of light touch or no touch, to improve wellbeing.

Reflexology: massage to ease tension and symptoms, based on the belief that reflex points in your feet, hands and head are linked to other parts of your body.

Shiatsu and acupressure: based on the same principles as acupuncture, in which pressure is applied to certain points of the body.

CARE INFORMATION FINDER

Search for resources with our Care information finder: **www.mndassociation.org/careinfofinder** or order printed copies from our MND Connect helpline: **0808 802 6262 mndconnect@mndassociation.org**

REFOCUSING ON STRATEGY AND BRAND FOR THE ROAD AHEAD

We carried out surveys, workshops and one-to-one conversations with more than 5,500 people to gather insights into how the Association presents itself

Seizing the opportunity

This year sees the MND Association in a stronger position than ever and in an ideal place to build on decades of hard work that has created positive change.

Our focus on research, support and influencing has resonated with the MND community and the public, bringing financial stability, collaboration opportunities and a voice to influence.

Now our attention is turning to the next five years, with a new strategy injecting a renewed sense of urgency and focus on our three core activities: Tomorrow's Treatment; My Support, My Way; Influencing High Quality Care.

More than four decades of work in these areas, and the raised awareness we've benefited from in recent years, has put us in the best place possible to drive more impact for people affected by MND.

Our strategy is our roadmap and we're already on the journey. We're reviewing and reforming our national support service to help us meet increasing demand and identifying new partners to support our ambitions. We'll be working closely with our dedicated volunteers to ensure people with MND, wherever they live, receive the support they want when they want it. And we'll be implementing a new research strategy to build on the investment we've already made in identifying causes and potential treatments for motor neurone disease. We'll be investing in new systems to streamline our processes and help our committed staff do their jobs brilliantly.

To ensure we have the funds and platforms to deliver our ambitious plans, it's vital we build on the awareness and fundraising momentum we currently have. To do that, we need to be more appealing to people who don't already engage with us so we'll be refreshing the way we look and the way we present ourselves, adding a dose of urgency and dynamism, while keeping a firm hold of our name and the legacy that has got us to this point. More about that on the next page.

While making these changes, we're also focusing on finding the balance – continuing to deliver what our community rightly demands of us while looking to the future.

Our look and feel – what you told us

More than 5,500 people have shared their thoughts about how the MND Association presents itself. That insight, via surveys, workshops and one-to-one conversations has helped us understand how we're seen and understood by the MND community, and also by people we want and need to work more closely with to deliver on our ambitions.

This has given us extremely valuable insight - thank you to everyone who made time to get involved.

The message we heard the loudest was how much the Association means to the MND community. Our experience, commitment and dedication are valued and you see us as a compassionate, caring and understanding charity, something we're incredibly proud of.

You also told us the way we look and feel can sometimes make us seem 'corporate', 'cold', 'dated' and 'inflexible'. And while you wanted us to keep the compassion and the caring, you also wanted us to feel more innovative and fast-moving.

As part of this work, we've consulted with experts about our logo. They told us it's not flexible or accessible enough – for example, it can be difficult to read when it's shrunk on social media and the shape doesn't suit a number of ways we, and our community, want to use it.

We also surveyed the general public to ask what they thought. A logo is like the sign above a shop – its value is in making a good first impression and grabbing attention.

We showed our logo alongside nine other charity logos. Ours was the one which the fewest people felt compelled to find out more about. While many of us have become fond of our logo, we need to consider changing it if we're to continue to reach enough people to have the impact our community needs us to.

Developing how we present ourselves will help support the ambitions we have, as an Association, and for the MND community. A new look and feel will reflect our heritage while clearly demonstrating the sense of urgency and dynamism we need to deliver on our Promises.

The next steps of the process are now underway. We will be reaching out to people in our community again over the coming weeks to work with us on that.

REGIONAL ROADSHOWS 2025

Following last year's successful programme of regional roadshows across England, Wales and Northern Ireland, we are delighted to be hosting two more events this year. And we'll be travelling to different regions to reflect the breadth of our regional volunteer base.

These face-to-face events are a great opportunity to hear more about the future direction of the Association and our priorities for people living with MND. Members of our Executive Leadership Team will be on hand to share our plans to continue to support the MND community, including our strategy, developments in MND research, and our campaigns work for 2025.

Please visit www.mndassociation.org/get-involved/volunteering/regional-roadshows-2025 to register your interest in this year's roadshow events

The dates and venues for this year's roadshows are:

Tuesday 13 May – Hilton Liverpool City Centre

Tuesday 10 June – The Delta by Marriott Cheltenham Chase, Gloucester

We're already planning our roadshows for 2026 with a view to visiting different regions again next year.

MND COMMUNITY GETS READY TO RUN FOR ROB

Runners from across the UK are in the final stages of their preparation as they come together to celebrate the life of Association patron Rob Burrow CBE.

The Rob Burrow Leeds Marathon will be held in the city over the weekend of 10 and 11 May, with more than 1,000 of the runners choosing to raise money on behalf of the MND Association.

This year's marathon weekend promises to be particularly poignant, taking place almost a year after the death of Leeds Rhinos legend Rob, from MND, aged just 41. On the Saturday, an MND Mile will take place at the Leeds Beckett University Headingley Campus for people from the MND community to join. The following day, a marathon relay will also be held alongside the half marathon and full marathon, with teams of seven tackling the 26.2-mile course.

Among those taking part in the Rob Burrow Leeds Marathon for the first time is Andrew Gough, who was diagnosed with Primary Lateral Sclerosis (PLS) last year. Andrew will be pushed around the course by his son, Matthew and other members of their team, Clan Gough. Together they aim to raise £7,777 to support the work of the Association's West Yorkshire Branch.

Andrew said: "We train around Wakefield every Saturday and we also took part in the Wakefield Hospice 10k in March which was really good for us.

"I used to do a lot of running, including the Great North Run, and I'm looking forward to joining the Rob Burrow Leeds Marathon for the first time with the rest of Clan Gough. I've known the Burrow family for a long time, and I've been inspired to get involved by Rob and his story. I know it will be emotional for me but I'm sure it will be a wonderful experience."

For the third consecutive year, the MND Association is a charity partner for the event, which is run by Jane Tomlinson's Run for All, in partnership with Clarion. To date more than £2 million has been raised, allowing the Association to improve support for people living with and affected by MND and invest more into world class MND research.

This year's marathon weekend promises to be particularly poignant, taking place almost a year after the death of Leeds Rhinos legend Rob, from MND, aged just 41.

For more information visit www.mndassociation.org/runforrob

“IT’S MY GREATEST WISH TO HELP FUND A CURE”

In the spring of 2023, Rob Steele received the devastating news that he had MND. It was a shock to him and his family, but Rob channelled his energy into fundraising and galvanised his friends to do the same.

Since then, Rob, supported by his family and friends, has raised a staggering amount for the MND Association and My Name’5 Doddie Foundation.

Rob’s children say, “Dad is a kind, generous and selfless man who has always contributed to his local community. Mum and Dad have had to constantly adapt to Dad’s progression of this disease and we are so proud of how they are coping and how they look to find a positive in each and every day!

“In true Dad style, instead of letting MND get the better of him, in August 2023 he decided to host an “Uno Mas” (Spanish for ‘one more’) party for 600 people at the Tonbridge Angels Football Club to raise money for the two charities. The event was a resounding success, raising over £70,000.”

But Rob wasn’t done yet. In May 2024, he was at the start line cheering on a group of local people from Tonbridge, Rob’s dearest friends, embarking on a new fundraising challenge; a long-distance walk from Twickenham Stadium to the South Coast, and around the Isle of Wight, covering a total of 150 miles in just seven days.

The team, known as 150MND was formed and has raised over £77,000.

The Tonbridge Angels Football Club that Rob is a long-time supporter of, and previously owned, joined the fundraising initiative, adding the MND Association logo to their third team kit.

The 150MND team has also held two quiz nights and, in association with the Tonbridge Round Table, Rob had the honour of opening the Tonbridge Fireworks, a major annual event in the town. These efforts have raised an additional £6,000 for MND charities… and the quest continues!

Rob said: “It’s my greatest wish and legacy to help fund a cure and raise awareness of this awful disease. My dearest friends have been incredible since learning the news of my diagnosis and are instrumental to the fundraising efforts, with more projects in the planning. I am overwhelmed by their support and how they are running with this for the future. Let’s continue to raise awareness and funds for this cruel disease.”

Visit www.150mnd.com to read updates from Team 150MND

Top: Rob pictured centre, at the start of the Twickenham to Isle of Wight walking challenge Below: Rob with Team 150MND

> **“It’s my greatest wish and legacy to help fund a cure and raise awareness of this awful disease.”**
>
> Rob Steele

I’VE SUPPORTED 150MND
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150MND.COM
HELPING THE MND COMMUNITY

HIKING FOR HUGH

On a foggy November morning, a group of friends and family gathered in Monmouthshire to climb Pen Y Fan, South Wales' highest peak. This was not just any hike, but a special hike inspired by Hugh Stewart, a keen hillwalker before his diagnosis of MND.

Friends and family before climbing Pen Y fan in South Wales

As the group set off from the car park, they were joined by people from all corners of the UK, as well as a surprise guest, a friend who had flown all the way from Colombia to join them. Despite the uncertainty of the weather, the team was determined to complete the challenge. Their motivation? To raise as much money as possible for the South East Wales Branch of the MND Association.

Helen Pemberton, Hugh's cousin describes the journey: "We started at 8:30am sharp, but I soon realised that I would be the slowest walker in the group. The climb was challenging, with thick fog reducing visibility and icy winds numbing our hands. We passed other walkers, including some brave fell runners in nothing but shorts and t-shirts, before reaching a cairn we mistakenly thought marked the summit. It turned out to be Corn Du, not Pen Y Fan. But we pushed on!"

After more climbing, the team finally reached their destination, at 9:55am. Helen said: "The weather may have been dreadful, but the support of my friends and family kept me going."

The hike raised over £15,500 for the local branch which has been supporting Hugh and his family since his diagnosis.

"THE RESOURCES HAVE BEEN A FANTASTIC INSPIRATION"

Above: an Association Treasure Box resource inspired Theo and his family to create memories together Right: Theo, his mum Karen and his Nan

Karen lives with her husband, 10-year-old son Theo, and her parents, who moved in at the start of the lockdown.

When her mum was diagnosed with MND in May last year, Karen became increasingly concerned about how the disease would affect Theo. As he watches his grandmother's symptoms progress, Theo has had to come to terms with the reality of MND and its impact on their family.

Karen said: "My son has been at the heart of all our concerns, especially since he sees everything first-hand with my mum living here. Everyone's been so thoughtful about making sure he's doing okay, and I'm grateful for the incredible support we've had."

When Karen's mum was first diagnosed, Karen struggled to find the right way to explain MND to Theo. She said: "I remember going through a guidebook on MND and thinking, 'how do I even explain this to him?' I reached out to a friend whose mum also has MND, and she suggested connecting with the Children and Young People's team at the MND Association because they have resources specifically for kids."

Karen spoke to Laura Willix, the Association's Children and Young People's Service Development Manager, who shared the Association's resources for children and young people. This included the charity's *My Treasure Box*, a memory box designed to help children build positive memories about the person they know with MND.

Karen said: "Laura has been wonderful. She sent over the memory box kit, which arrived at the perfect time. Theo had been working on a family tree project at school and asked about everyone's favourite colours, which made me realise I didn't even know my mum's.

"When the box arrived, it had all these little prompts and keepsakes which we've been working on together in a nice, light-hearted way. The resources have been a fantastic inspiration for us as a family and has even prompted my mum to start dictating her own life story."

Laura has also helped Theo at school by equipping his teachers with information and guidance on how best to support him. Theo now has regular one-to-one sessions at school and his teacher has taken the time to study an MND book so he could answer questions Theo might have. Karen continues: "His teacher has been incredible. He even took the book home to study it, which was really thoughtful."

For Theo, MND has become part of his daily life. He has developed friendships with his Nan's carers, who make a point of playing with him, and he's become a regular rider on the stairlift.

While the experience has been devasting for the family, Theo's naturally caring nature has shone through. Karen said: "He's so thoughtful. Just the other day, he helped Mum up when she was stuck under the covers, giving her a drink without even being asked. He's instinctively stepped into this role, which is both heartwarming and tough. It's hard knowing he'll eventually lose his Nan, as every child does, but for him, living with her has brought out his nurturing side, which is really beautiful."

For information on the MND Association's Children and Young People resources visit

www.mndassociation.org/support-and-information/children-and-young-people

MAKING EATING, DRINKING AND SWALLOWING SAFER

Kirsty Harrison

> **“There has been some valuable research into tube feeding but, by comparison, relatively little about eating, drinking and swallowing in MND.”**
> Kirsty Harrison

Around 25% of people with MND opt for tube feeding

The MND Association, in partnership with the National Institute for Health and Social Care Research (NIHR), has awarded the first jointly funded Doctoral Fellowship to Kirsty Harrison, a speech and language therapist.

This is the first fellowship offered under our new research charity partnership with the NIHR to investigate ways to improve the lives of people living with MND. Through this partnership we aim to attract, retain and develop current health and social care professionals by providing opportunities for them to continue or start their careers in MND research.

Most people with MND experience swallowing difficulties. This can lead to complications such as weight loss, social isolation and respiratory infections. Around 25% of people with MND opt for tube feeding. Most continue to eat and drink orally, which can cause significant risks and challenges.

Kirsty's research aims to make eating, drinking and swallowing easier, safer and more enjoyable. A resource, likely a website will be created offering evidence-based strategies and resources to manage eating and swallowing. For people with MND and their families, this will equip them with information to make informed decisions.

Kirsty said: “There has been some valuable research into tube feeding but, by comparison, relatively little about eating, drinking and swallowing in MND. I hope this project will shine a light on the research gaps and give people more choice. The digital resource will provide support, information and strategies to learn about what has helped other people with MND managing changes to their swallowing.”

The experiences of people living with MND are a key part of the project, as Kirsty explains: “Talking to people living with MND helped to shape this research idea and ensure it was grounded in what people wanted and needed. People with MND will also be part of the co-development group overseeing the project. They will help to shape the research and inform how the information is presented on the website.”

Kirsty's three-year fellowship began in January 2025. She said: “I hope the website will be a go-to resource for support and advice used by people with MND, their loved ones and health professionals.”

Dr Sophie Nyberg, Research Programmes and Partnerships Manager at the MND Association said: “We are delighted to fund this research by Kirsty that could lead to improved care of people living with MND. This fellowship also adds a new dimension to the MND Association portfolio and is the first health and social care research fellowship we have offered. By attracting, retaining and developing health and social care professionals, we're aiming to discover new ways to help people diagnosed with this devastating disease.”

IMPROVING CARE FOR PEOPLE WITH MND IN LINCOLNSHIRE

The MND Association is funding three new community-based MND co-ordinators to fill a gap in vital services in Lincolnshire.

Currently people with MND living in Lincolnshire, a large, rural county in the east of England, have limited access to co-ordinated services or specialist MND healthcare professionals. Poor public transport links exacerbate the challenges people face accessing specialist care.

That's set to change with the introduction of three co-ordinator roles, paid for by the MND Association, to address the inequity.

Teresa Purkis and Josephine (Josy) Magumbezi, both with backgrounds in occupational therapy, began their roles in March. They will cover the area served by the Lincolnshire Integrated Care Board, while a separate co-ordinator will be appointed to serve the Unitary Authority areas of North Lincolnshire and North East Lincolnshire.

Teresa, Josy and a third co-ordinator (when appointed) will work across local health services and hospitals to ensure people living with MND receive the type of multidisciplinary care which people who live in the catchment area of one of the 24 MND Association funded Care Centres and Networks receive as standard. They will co-ordinate multidisciplinary teams, improve care pathways to ensure they are effective and accessible to all people with MND, while sharing and promoting best practice with health and social care professionals.

Josy said: "I'm looking forward to working with people with MND, their families and other professionals to improve services for people with MND in the area. Ultimately it is about positively impacting people's lives and working hard to enhance their quality of life."

For people with MND, their families and the health and social care professionals supporting them, Teresa, Josy and their new colleague will introduce a single point of contact and a link to local MND Association support groups.

Teresa said: "I am so excited to be starting the new MND Co-ordinator role with Josie, and getting to know people in Lincolnshire with MND and their families who I haven't yet met, as well as reconnecting with familiar faces.

"I hope this role will provide consistency in support for people living with MND in Lincolnshire. I will be looking to help smooth out those areas where there have been delays or difficulties in accessing the right services when they are needed."

The MND Association is continuing work on identifying other areas of need where investment could support the development of community-based services.

Teresa and Josy can be contacted on 01522 573995

"I am so excited to be starting the new MND Co-ordinator role with Josie, and getting to know people in Lincolnshire with MND and their families."

Teresa Purkis

"I'm looking forward to working with people with MND, their families and other professionals to improve services for people with MND in the area."

Josy Magumbezi

THE RESTORATIVE POWER OF GARDENS

Gardens mean different things to different people. For some, they are a place to observe wildlife, for others a peaceful space for reflection. Here, three people living with MND tell us what their open spaces give them.

Simon Farrell

"I've always enjoyed being outside and I get a lot of energy from it. I do feel frustrated I can no longer garden because of my MND, but I feel fortunate I'm still able to enjoy it.

When you look around intently, you see things you'd otherwise miss. There is a patch of wildflower meadow where I can see the plants beginning to stir. Just looking at a primrose - it's so beautiful and rewarding, it can only boost your mental health.

Before MND I built an Iron Age roundhouse using local materials. It's surrounded by the wildflower garden. The beauty of creating a wildflower garden is that it's low maintenance. People call them weeds, but they are simply native wildflowers. All completely magical and I welcome them."

Diana Keys

"My Association visitor Emma told me about MND Association support grants and how one could help me to make my garden safe as my symptoms progressed.

When the grant came through, it was so exciting, and I got to work on the design. The finished garden has made a positive difference to me and my family now I can access it safely with my walker.

I'm able to find joy in so many things like watching the birds at the feeder, or my cat Dylan, drinking from the pond. The garden makes me feel at peace and a tad proud of myself to have made such a beautiful space. I will be making the most of sitting quietly and counting my blessings."

Susan Read

"When my husband Laurie and I moved into our home in 1988, the garden was just a field. Gardens are a form of autobiography, and we began writing ours. Over time we created a beautiful garden together.

Those were my happiest years and by planting and working on our garden together it showed that we believed in tomorrow. Sadly, Laurie died in 2014, so I continued to garden on my own until last year, when I was diagnosed with MND.

I can no longer garden, which is a huge loss, so now I simply watch and enjoy the garden and the birds. The other morning, I sat in the sunshine and said to my friend 'this garden will save my sanity' and I really believe it will."

ACCESSIBLE GARDEN TIPS

Award-winning garden designer Sue Hayward has designed three MND Association gardens at the RHS Chelsea Flower Show. Here, she shares some tips for creating accessible gardens.

Wide paths and smooth surfaces: Create interlocking paths where wheelchairs can turn. Even in smaller spaces, a path can lead to a point of interest, such as a bird feeder or water feature.

Encourage wildlife: Planting wildflowers and installing bird feeders attract wildlife.

Think about sounds: Listening to running water can feel soothing and help to mask external noise.

Consider eye-height and vertical planting: Raised beds create interest at different levels. Vertical planting can add dimension and create areas where you can feel enclosed in nature. Trees can form a beautiful canopy.

Bring the outdoors in: Create a space you can see from your window – a bird feeder or bird bath can transform a view.

APPLY FOR A GARDEN GRANT

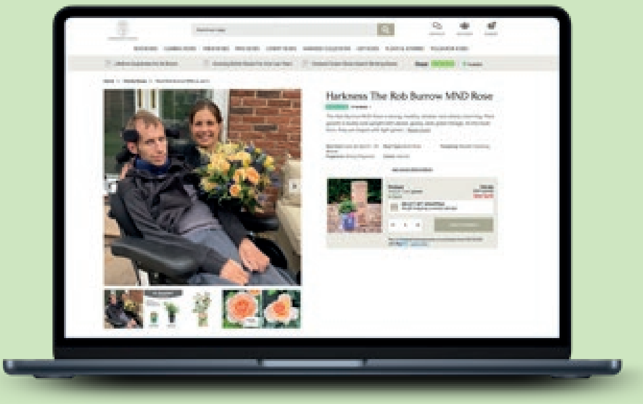
Last year we received 74 applications and provided grants totalling £32,045 towards garden improvements.

You can apply for a grant to help make your garden more accessible by scanning the QR code or contacting MND Connect on 0808 802 6262.

ROB BURROW MND ROSE

The MND Association receives **£2.50 from the sale of every Rob Burrow MND Rose**, created by The Harkness Rose Company, pictured left with donations in 2024 totalling **£14,500.**

Just scan the QR code to buy the rose or visit www.roses.co.uk/product/531102/rose-rob-burrow-mnd-4l-pot-c



WHAT YOUR GARDEN MEANS TO YOU

We asked you on social media what your garden means to you. Here's what you told us, along with some tips you shared.

"I'm now buying more perennials so that, as I face more difficulties, I will not need to plant so much. I've also bought a seat/stool to allow me to get up from the floor and allow more time for everything."

"My husband couldn't continue to use the petrol lawn mower, so we bought a lightweight lawnmower."

"The MND Association support grant enriched Mum's life. It helped towards hiring a wheelchair adapted van for her to go on a family holiday and towards purchasing a ramp for the garden. It meant she could still get out in her wheelchair to spend time in the garden that she loved."

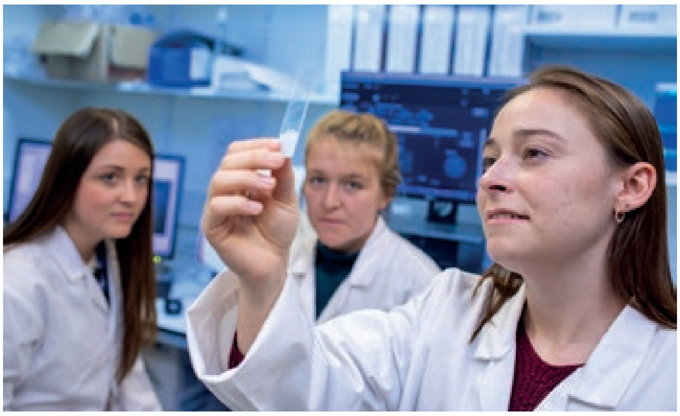
"My husband has actually got into gardening since he was diagnosed. He's only 43. But he is finding it difficult as his arms aren't working well. As it turns out, one of his carers is a landscaper and he loves nothing but spending time with him in the garden. He's a legend and my hubby loves it."

"Running the plant nursery was the thing that kept my partner going. When he was diagnosed, several of our customers volunteered to help. They kept my partner and I, plus the nursery going. We were so lucky to have a nursery and to have such amazing support. My partner was able to keep engaged in life until the week he died."

GET INVOLVED IN MND RESEARCH

MND research wouldn't be possible without the involvement of people living with MND, their families, carers and healthy volunteers.

Researchers rely on the dedication, generosity and commitment of the whole MND community to understand the causes of MND, and improve diagnosis, care and quality of life of people affected by the disease. There are many ways you can get involved in MND research, from filling out a survey to testing a new treatment.



Take part in a workshop to help design a tool to support cough and secretion management

Researchers from the University of Sheffield are looking for people with MND, family members, carers and healthcare professionals to take part in a workshop to share their thoughts and ideas on a new tool being developed to help manage cough and secretion problems.

FIND OUT MORE ABOUT THIS STUDY AND HOW TO TAKE PART

www.mndassociation.org/developing-tool-support-cough-and-secretion-management-mnd

See our webpage for more ways to get involved in research: **www.mndassociation.org/research/get-involved-in-research/take-part-in-research**

CALLING FOR REFORM FOR MND CARERS


Tanya Curry, Chief Executive, MND Association

As of May 2024, 134,800 claimants were in debt to the Department of Work and Pensions (DWP) due to overpayments, with a total value of

£251million

The MND Association has given evidence to the Government's independent review into Carer's Allowance overpayments, which have affected carers in the MND community.

The committee, announced last October by Work and Pensions Secretary Liz Kendall MP, is led by Liz Sayce OBE, the former Chief Executive of Disability Rights UK.

It has been investigating causes, impacts and potential solutions into the overpayments, which was revealed last year by *The Guardian*. As of May 2024, 134,800 claimants were in debt to the Department of Work and Pensions (DWP) due to overpayments, with a total value of £251m.

People with MND and their families have been directly caught up in the overpayment issues. Overpayments often occur when a carer exceeds the eligibility limit by earning above the threshold or reaches pensionable age. In some cases, carers have been left to repay thousands of pounds.

The Association first raised the issue with Sir Stephen Timms, Minister for Social Security and Disability, in November 2024. Our Chief Executive, Tanya Curry gave evidence to the committee in February, sharing stories of MND carers who have been forced to repay large sums due to the DWP error.

One person, whose wife has MND, received a letter from DWP saying he owed £2,400, without any clear explanation of how the debt accrued or how to resolve it. Another, who cared for her husband, received a demand from the DWP to repay four weeks of Carer's Allowance shortly after his death.

The overpayment recovery process failed to recognise the emotional and financial strain on carers. The committee is expected to deliver its findings and recommendations to ministers this summer.

Tanya said: "We have set out clear, tangible changes that the DWP can enact to prevent these overpayments from happening.

"Improved monitoring and communications and a review into the impact of fluctuations in earnings are just two factors we have raised in our submission.

"We are grateful to have been asked to address the committee and look forward to a serious discussion about reforming a broken system."

To punish carers for making a genuine mistake, while trying to look after their loved ones in the most difficult period of their lives, is not only wrong but downright cruel.

Tanya Curry, Chief Executive, MND Association

MND-SMART: ACCELERATING ACCESS TO PROMISING TRIAL DRUGS

MND-SMART, the UK's first MND 'platform trial' is accelerating access to promising new drugs. Alongside increasing the pace and efficiency of drug testing, it marks a significant step forward in the creation of a robust, UK-wide research infrastructure.

MND-SMART is initially trialling repurposed medicines which are safe and already used to treat other diseases. Since its launch in 2020, the MND-SMART trial team has opened 22 trial sites across the UK.

By testing a range of drugs at the same time and comparing each treatment to a single control group receiving a placebo, it maximises the number of people who are given potential new treatments while minimising those on placebos. If a drug shows no effect, it can be quickly dropped, and a new one introduced.

Memantine and trazodone are two drugs that have been removed early after failing to slow the progress of MND. However, the trial into amantadine, a drug that is currently used in Parkinson's, multiple sclerosis and influenza, continues. If this drug proves effective this, and other repurposed drugs, could be taken forwards as MND treatment options.

More UK trial sites will open this year, increasing opportunities for people with MND to participate in clinical drug trials. Over 900 participants have so far been recruited to take part in MND-SMART.

For some participants, MND-SMART offers more than just access to potential new drugs.

Steve Barrett OBE, is a member of the MND-SMART Participant Advisory Group. He said: "The trial feels like part of my overall care package. The opportunity to meet with the research team, together with the repeated completion of testing and blood sampling, gives me an up-to-date measure of any progression. For myself and my family, it also creates a sense of hope, a life jacket, that prevents us from emotionally drowning."

MND-SMART is led by the Euan MacDonald Centre for MND Research at the University of Edinburgh. The MND Association is one of the funders of MND-SMART, alongside MND Scotland and the My Name'5 Doddie Foundation.

GLOBAL MND AWARENESS DAY 2025

On 21 June, as every year, we will mark Global MND Awareness Day. We will be working hard to put MND in the spotlight, raising awareness of the disease, its impact and the people in our community.

We'll be working with the media and sharing lots of information on our website and social media channels. We'd love you to join us. Look out for ways to get involved and spread the word among your family, friends and networks.

“IT’S CRUCIAL TO STAY ONE STEP AHEAD OF MND”

Jacky Smith, enjoying time in her accessible garden

On 18 September 2008 at five minutes to nine, Jacky Smith’s life changed forever. The strong and sporty police inspector was told she had MND. The diagnosis brought an abrupt end to Jacky’s 24-year career and started a journey of continually adjusting to the progression of her MND. Here, Jacky tells her story.

“Things moved very quickly after my diagnosis. I was given a wheelchair, and at the time I thought, ‘I don’t need that, I’m managing to walk using the furniture at home very nicely!’ I put it in the corner and was sure that’s where it would stay.

As soon as I was given the diagnosis, I let the Force know. They’d been asking me what was going on leading up to it because I was so weak. When I said it was MND they told me they would retire me in six months. They were always so good to me, and I was grateful for their support.

Retiring from the job I loved was the hardest. An MND Association visitor came round and asked me what I needed, but at the time I just didn’t know. I was feeling lost. It was awful, the worst day ever, but she supported me through it.

I tried to keep my mobility and independence as long as I could. I went on crutches, then a frame, and around 12 months later, I was in the wheelchair. I love my wheelchair now and wouldn’t be without it.

I got a new wheelchair recently and I was quite sad to see the old one go. It was falling apart, but it had been on many adventures with me and had lots of battery changes and new tyres because of it. It was like Trigger’s broom (from the television comedy *Only Fools and Horses*) with how many bits had been swapped and changed throughout the years.

When I first needed a wheelchair, I resisted it, but I eventually accepted that it was the right decision. Recently, I got a specialist chair for the lounge. At first, I had some problems with it, but now, with my severe osteoporosis, it’s become useful. I sit in it twice a day, just for an hour, but it makes a difference.

I’m currently volunteering in two roles for my local support group, the Herefordshire and Worcestershire Group. I help with social media and I’m also the group administrator. I was a project manager in the police, so this role is perfect for me. I keep everything on track and send out a newsletter every three months. It’s really helped my wellbeing. I feel like I have a reason to be here by giving something back.

It’s crucial to stay one step ahead of the disease. Know what’s coming, get your head around it, and get the right equipment in place because sometimes things take a long time to arrive. I’d also say take advantage of everything that’s available. I was slow to realise what the MND Association offered, and I could have been much more comfortable had I known sooner.”

“It’s crucial to stay one step ahead of the disease. Know what’s coming, get your head around it, and get the right equipment in place because sometimes things take a long time to arrive.”

Jacky Smith

SPOTLIGHT ON: THE WIRRAL GROUP

Debbie Williams and Julienne McGeough

Debbie Williams, Chair of the Wirral Group, and group member Julienne McGeough, discuss how they have introduced a new initiative to recruit volunteers to their area.

Considering the volunteering landscape

Debbie: When a member of the Group retired last year, it really brought to the surface the issue of the demographic of our volunteers. We were struggling to replace people when they moved on. It became clear we needed someone specifically to concentrate on recruiting volunteers. This is where Julienne, who has experience of volunteering elsewhere, came in.

Julienne: The Group is doing really well, but we knew that if some of our amazing long-standing members stepped down from their committee roles we would see the impact. We knew we needed to shift our focus to non-committee roles to support our long-standing committee members who were juggling their roles with full-time jobs.

Debbie: Our Group is structured so we already have a system of shadowing, so people can step in at short notice. However, we don't always have enough volunteers to support our programme of fundraising events.

Occasional volunteers

Julienne: We wanted to take a different approach. Volunteering is a big commitment and some of our previous ways of attracting people, for example contacting university students by email, weren't working.

We landed on the idea of asking for occasional volunteers who could give three hours a year. And it's really resonated with people. It's allowed us to ask people at any of our functions to make a three-hour commitment to try it as a one-off and see how it feels to be part of our Group.

Debbie: On the day Kevin Sinfield CBE ran through the area last year during his 7 in 7 challenge, 12 people signed up! We followed up with a call and then invited them to our Occasional Volunteers WhatsApp group where we post our activities. If something on there piques their interest, they can get in touch to offer their three hours. To date we've had six new volunteers take part.

It's a difficult landscape for attracting volunteers right now and, for us, reducing the volunteering ask in this way has made a big change.

Success and takeaways

Debbie: We held 30 fundraising events last year and raised around £100,000. For a small Group in a small area, we're doing really well. The challenge is maintaining that. I feel this initiative is a good way forward for people to get involved in the way they want.

Julienne: Our hope longer-term is that some of our occasional volunteers could eventually step up to take a leadership role. If we recruit 20-25 occasional volunteers, for example, and two or three want to get more involved, that's a massive win.

RESEARCH PROJECT SPOTLIGHT

MND is a complex disease so the research we fund needs to cover a broad spectrum, from searching for causes to finding treatments and exploring ways of easing symptoms. Here's a snapshot of some of the most promising MND Association funded research underway right now.

Scan the QR code to visit our website and read about these projects and others we fund.

Dr Alisdair McNeil

Developing resources to support sharing of genetic test results in MND

Previous research into the complexity, impact and difficulties of discussing genetic testing has revealed families find it hard to talk about this topic and may avoid sharing genetic test results with other family members. Dr Alisdair McNeil, from the University of Sheffield, is looking to gain a better understanding of people's experiences of genetic testing in MND to understand their views on sharing information and what support they need when talking about gene changes in MND. It is hoped this information will be used to create online resources to help people with MND feel more comfortable having discussions with their families about gene changes.

Investigating faulty protein production in MND

All proteins that are made in cells are made on a production line in the body, and a protein called TDP-43 plays an important role early on in this manufacturing process. In MND, TDP-43 stops working at its correct place on the production line in the body, which can cause errors to the proteins being made. Dr Ashkay Bhinge, from the University of Exeter, is exploring how TDP-43 causes problems in motor neurones when it stops working properly and how this might contribute to the development and progression of MND. Understanding more about the changes caused by TDP43 in MND could help to identify ways to reverse these changes, which might improve the health of motor neurones and lead to new potential treatments in the future.

Dr Sara Mazzucco

Managing choking in people living with MND

MND can affect muscles in the throat and chest, which causes difficulty breathing, coughing and swallowing. Choking, where breathing becomes difficult due to airway blockage, may happen more frequently and be more severe in people living with MND. This can lead to emergency calls, hospital admissions, and unplanned medical procedures. Dr Sara Mazzucco, from the Great Western Hospital Foundation Trust, is developing guidance on choking, specifically for people living with and affected by MND. Through talking to people living with MND, their carers and healthcare professionals, new guidance will be developed to ensure that there are clear, standardised guidelines.

Understanding the role of changes in the TBK1 gene in MND

TBK1 is a gene that has been associated with MND, but it's not clear what its role is. One theory is that changes in TBK1 may lead to different versions of proteins being made from the same gene. These proteins can cause damage within neurones. Dr Sarah Langley and her PhD student, Sophie Shaw, at Cardiff University will investigate how changes in TBK1 in motor neurones and microglia (which support motor neurones) might cause damage to the cells and contribute to the development of MND. Understanding more about the role that changes in TBK1 may play in MND could help to identify new targets for the development of potential treatments for the disease.

FUNDRAISER INSPIRED BY ED

In January, 60 colleagues from 34 companies working within the data centre industry came together for an extraordinary fundraising event at Rebel1 in London. The charity spinning class was held to show support to Ed Cooke, MND Association trustee, who died from MND in February, less than two years after his diagnosis.

Organised by Richard Irwin and Holly Fenner from GeN+1, the event was a true testament to the power of community and generosity.

Richard said: "When Ed first shared the news of his MND diagnosis, I was approached by two of his friends to see if we could host a fundraising event. I also had the privilege of knowing Ed for many years and always looked forward to meeting him at industry events. So the opportunity to organise the charity spin event in support of him meant a lot to me."

Participants secured their place by contributing £50 per spinning bike. Their combined efforts resulted in an incredible £14,019 raised for the MND Association - funds that will go towards vital research and support for those affected by the devastating disease.

Inspired by the success of the event, GeN+1 organised a spring Padel tournament in Slough, and a summer Pedalling for a Purpose cycle event in Cannes, as a tribute to Ed's legacy and has also chosen the MND Association as its Charity of the Year.

REGISTER NOW TO JOIN US AT MND ENCOURAGE UK 2025

This year's event is being held in Leicestershire, and we will be welcoming people living with or affected by MND to join us from lunchtime on Wednesday 16 July.

Registration for MND EnCouRage UK is now open, offering people from the MND community the opportunity to join some of the brightest scientific minds at this special event.

MND EnCouRage UK, now in its fourth year, brings together early career researchers (ECRs), people with MND and established researchers for a unique two-day event.

During the event, you'll hear from 22 of the brightest and best ECRs who have chosen MND as their field of study. You will also take part in a roundtable discussion about clinical trials, listen to leading MND researchers discuss topics important to the MND community, and learn how the MND Association is driving progress in research. Finally, you can put your questions directly to senior researchers, scientists and clinicians.

Describing the event, Professor Ammar-Al Chalabi, Professor of Neurology and Complex Disease Genetics at King's College London said: "I always love attending MND EnCouRage. It is a wonderful combination of ECRs full of enthusiasm, more established scientists, and people living with and affected by MND, all able to share their experiences, ask questions and provide insights."

Centre and right, Anna who is living with MND and husband Martyn Barrow who took part in last year's MND EnCouRage UK event

Registration will open on 24 April on our website. Places are limited so if demand is greater than spaces available, names will be entered into a ballot. www.mndassociation.org/research/research/mnd-encourage-uk-2025

APPEALS RAISE MORE THAN £1 MILLION IN 2024

Matthew
(June Appeal)

Tim, Jess and Olivia
(Summer Appeal)

Peter and Jake
(September Appeal)

> **"We are so grateful to everyone who chose to donate to one of our appeals last year."**
>
> Alison Holmes, Direct Marketing Manager, MND Association

Alex and Laura with their family (previous Christmas Appeal)

Eoin and Jenny, with their children who featured in our 2024 Christmas Appeal

More than £1 million was raised through the MND Association's fundraising appeals in 2024 helping to improve support and fund vital research into MND.

The Christmas Appeal, which featured Eoin, who is living with MND, his wife Jenny and their two children, helped to raise a record-breaking £355,000 which could help to support the Association's voice-banking service.

As part of the appeal, Eoin, who was diagnosed with MND in 2020 explained how the MND Association had been able to help him bank his voice, retaining his Irish accent and an important sense of self.

Eoin said: "We were delighted to hear about the campaign's financial success but the idea that it could inspire others in our situation is very special to us."

Alison Holmes, the MND Association's Direct Marketing Manager said: "We are so grateful to everyone who chose to donate to one of our appeals last year. The money raised will have a huge impact, helping us to fund the services many people in our community rely on, while accelerating investment in MND research.

"Of course, none of this would be possible without the support of people living with MND and their families who have been so generous with their time, allowing us to share their own, very personal experiences of MND. We couldn't be more grateful for their support."

In March, the Association launched its most recent appeal which highlights the heartbreaking choices some people living with MND are being forced to make as a result of the cost-of-living crisis. In it, Diana, who is living with MND has shared her story and her experience of receiving a cost-of-living grant from the MND Association.

To learn more about the March Appeal visit www.mndassociation.org/march-appeal or to share your story email communications@mndassociation.org

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1985-2025

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WILL POWER OFFERS GIFT OF HOPE

Leaving a gift in your Will is one of the most powerful ways to show your support for the MND Association creating a lasting legacy of hope for generations to come.

That was the message to supporters who attended the Association's legacy event which was held at John Radcliffe Hospital in Oxford in February.

During the day, visitors heard from leading MND researchers who gave valuable insight into the progress being made in the fight against MND. Supporters were also able to view the laboratories, and speak with leading MND researchers including Professor Kevin Talbot, Dr Beatrix Cardus and Dr Björn Vahsen from the University of Oxford.

Dr Vahsen explained that none of his research, which is looking at stem cells, would be possible without the support of the MND Association.

Last year, gifts in Wills accounted for a quarter of the Association's fundraising income and allows the Association to invest in the research projects which give the greatest hope of a world free from MND.

The Association's next legacy event takes place on 14 May in Nottingham and registration is now open. To reserve a place, contact the legacy team on 01604 611799 or email legacies@mndassociation.org

Leaving a gift in your Will to the MND Association could make a future breakthrough possible, funding around a third of our work, your legacy is more important today than ever before.

To request your gift in Wills guide, please visit www.mndassociation.org/giftsinwills or contact us by phone 01604 611799 or email legacies@mndassociation.org.

LET'S TALK

Members of our Executive Leadership Team recently presented at our latest online Let's Talk event. Around 40 attendees listened to talks from Sally Hughes, Director of Services and Partnerships and Richard Evans, Director of Engagement about their upcoming priorities for the Association, including our campaigns and our work in response to last year's My MND, My Needs survey.

Richard Evans, Director of Engagement

Sally Hughes, Director of Services and Partnerships

'IT DOESN'T FEEL LIKE 25 YEARS'

Members of the Gwillym family (l-r) Ellan Sims, Deborah Gwillym, Irene Gwillym and Ann Williams. Irene is holding a newspaper article about the Branch's inception

When Branch Treasurer, Deborah Gwillym first heard about MND in 1999, there was no branch in South East Wales.

"My uncle, Michael Gwillym, was diagnosed with MND and we didn't know anything about it as a family. There was just no knowledge in our area," she said.

Deborah's father, Graham and family contacted the MND Association for help and discussed setting up a branch.

"For our first meeting, we put out some flyers and found quite a few people who had MND but didn't know what to do or where to go. My dad's family said they would like to set up a branch and as I was an accountant, my dad said, 'you could be treasurer'. My sister became secretary – Dad said to her, 'you can write a nice letter!'."

It's a role Deborah still fulfils, and it's been a family affair alongside her sister Ellan Sims, with her father and aunt Ann Williams volunteering as Association volunteers and her mother Irene Gwillym regularly helping out at meetings.

A place in the community

Since the early days, Deborah has seen the Branch's place in the community grow.

"We have a dedicated fundraiser now and two Association visitors. We promote the work of the Association and share knowledge where we can," she said.

The Branch works hard to promote itself through social media and makes sure everyone in the area with MND has access to assistance if they want it. "If we get a grant request, we deal with it as soon as we can as we know time is critical," she said.

In February, the Branch marked its achievements over the last 25 years at a special get together with Deborah and her family in attendance.

> **"It doesn't feel like 25 years since I started my role. It's just been so rewarding to be able to take part in our Branch events and raise funds. It's been a real privilege and rewarding in so many ways."**
>
> Deborah Gwillym, Branch Treasurer, South East Wales Branch

MAKING A SPLASH IN MAY

Lucy O'Reilly

Anita Jenkins

Jenny Gibbs

After running 31 miles in January and moving for 30 minutes a day in March our incredible fundraisers are preparing a day to don their swimsuits for their next challenge – swimming 6km in May.

Since the start of the year, #TeamMND has been out in force, braving the elements to raise awareness of motor neurone disease and the work the MND Association does to support all those affected. Together, by taking part in our Facebook challenges, they have raised more than £800,000 which will enable the Association to support many more people living with MND while also funding vital research.

81-year-old Jenny Gibbs was inspired to take part in Run 31 after her beloved son-in-law Adam was diagnosed with MND in July last year. She raised £2,400.

She explained: "His decline has been so rapid, it is shocking.

"Although I am doing all I can to help my daughter care for him, I feel so helpless and I am desperate to do something, anything, which might help.

"I saw the January challenge on Facebook and decided to give it a go. At 81, I can't run, so decided I would walk instead and gave myself the target of walking 100 miles. I certainly never expected I could do it, but I did, walking 102 miles in total. Likewise, I never expected to raise £150."

Anita Jenkins, whose husband Darrell died from MND six years ago was among those who took part in Move for 30 Minutes in March. While a spinal condition has stopped Anita from taking part in marathons, she was still keen in get involved and walked every morning with Nordic poles to help raise funds and awareness.

She said: "Since Darrell died, I've developed spinal stenosis which limits my mobility.

"When I saw the challenge I thought, 'I can do half an hour of exercise,' and the real challenge is doing it daily. It will help raise funds, hopefully, and kick-start me being more mobile and to get out and about in the fresh air. It's a win win."

#TeamMND's next big challenge will come in May when fundraisers are being invited to swim for 6km in May.

Swimmers can raise money in any way they choose, whether it's through open water swimming, clocking up lengths in their local pool or by taking a dip at their nearest beach. The challenge is open to anyone of any ability and fundraisers are encouraged to adapt it to suit their individual needs.

More information about our Facebook challenges can be found at www.mndassociation.org/facebookchallenges

BAKEIT! FOR MND THIS SPRING

Spring is the perfect time to bring people together over something sweet. Whether it's a simple bake sale, an afternoon tea, or homemade treats at work, every cake, cookie and cuppa can help support people living with MND.

You don't need to be an expert baker - gather friends, family, or colleagues and enjoy some good food for a great cause. You can choose to keep it simple with a coffee morning or go all out with a spring-themed spread of lemon cakes, hot cross buns, or pastel cupcakes. Add a raffle or bake-off challenge to make your event more engaging!

By taking part, you'll be helping fund vital research and support for people affected by MND. However you choose to bakeit! your support makes a big difference.

FREE
bakeit!
pack

Just scan the QR code below or simply head over to www.mndassociation.org/bakeit and grab your free bakeit! pack to get started!

CARE INFORMATION UPDATES

What is genetic testing?
This new animation gives an overview to help people with MND, or who have a family history of the condition, understand genetic counselling and genetic testing. Find all of our animations at: **www.mndassociation.org/animations**

Making the most of life with MND
We have revised our booklet on quality of life with MND or Kennedy's disease. It focuses on adapting your approach to find ways to continue doing things you enjoy. Find out more at: **www.mndassociation.org/relationships**

Personal care with MND
We've updated our booklet on managing everyday personal care, including guidance on equipment, services and support. Find the booklet and more information on personal care at: **www.mndassociation.org/personalcare**

Revisions
The following information sheets have been updated:

- *1B Health information in other languages and formats*
- *10A Benefits and entitlements*

How to find our information
Find our resources, including for professionals and research at: **www.mndassociation.org/publications** or order printed copies from our MND Connect helpline: **0808 802 6262, mndconnect@mndassociation.org**

To search for our resources by need, use our information finder at: **www.mndassociation.org/careinfofinder**

Our information development is accredited through the PIF Tick scheme. This means our resources are evidenced, user tested and reviewed by experts.

Trusted
Information
Creator
Patient Information Forum

Help our information development…
We work alongside people with MND or Kennedy's disease, and their carers, to develop and improve our information in a range of formats. Join our user reviewers and make a difference from the comfort of your own home.

Find out more from: **infofeedback@mndassociation.org**

EXPERTS-ALS RAPID DRUG SCREENING PROGRAMME UNDERWAY


Professor Martin Turner

Recruitment for an innovative experimental medicine programme to accelerate MND treatment development is now underway at six centres, with five more due to open this year. The first participant was recruited in November 2024.

The EXPERTS-ALS platform enables faster drug screening in people with MND. Participants will receive one of three drugs currently being tested - Metformin, Nifedipine and Ropinirole.

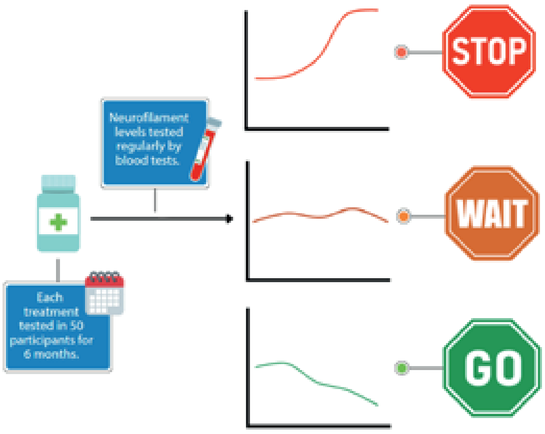
Led by Professors Martin Turner at the University of Oxford and UK MND RI Co-director Chris McDermott at the University of Sheffield, the programme is a flagship project of the UK MND Research Institute.

EXPERTS-ALS will assess drugs in eligible MND patients, identifying early signs of benefit. A decision can be made within months, with the most promising drugs prioritised for testing in larger phase 3 trials.

One of the signs being used in the study to tell if a drug is promising is a biological marker of disease activity called neurofilament light chain (NfL). Regular blood tests will track NfL levels, and drugs that significantly reduce them will be put forward for larger phase 3 trials, such as MND-SMART.

The programme is funded by £8 million from the Government as a part of the £50 million pledge resulting from the #United2EndMND campaign, with additional funding from the MND Association, LifeArc and My Name'5 Doddie Foundation to extend the length of the trial platform.

"We are delighted this programme is now open to eligible participants. This novel experimental medicine platform should help the research community better identify and prioritise drugs to be fast-tracked into clinical trials. This increases our chances of 'picking winners' that will have a genuine therapeutic impact for people living with MND." said Dr Brian Dickie, Chief Scientist at the MND Association.



THANK YOU

TO ALL OUR FUNDRAISERS

SOMEK AND ASSOCIATES

In 2024, Somek and Associates selected the MND Association as its charity of the year, following the death of their colleague Jenn's husband, Paul, from MND. The team held a Euros-style sweepstake, a Halloween-themed fundraiser took part in the Wendover Woods Parkrun and walked the Pendor Loop, raising £1,120.

REMEMBERING ALLAN

To mark 20 years since Allan Worswick, a farmer in Burnley, died from MND, son Neil and his hiking group took on the challenge of walking up Helvellyn, the third highest mountain in England in his memory and raised an amazing £18,000.

RUN WARREN RUN

On December 1, Warren Thomas ran the extra mile alongside MND Association patron Kevin Sinfield CBE during his 7 in 7 Challenge. The following day he ran 2 miles, then 3 - running a total of 496 miles by New Year's Eve. Warren's endeavours, supported by family and friends, raised £13,334.

RUNNING TRIBUTE

Steven Oldale ran the London Marathon in honour of his friend Gary Curtis. Sadly, Gary died before Steven completed the marathon. Steve's initial target was £2,700 but thanks to the generous support of family and friends he raised more than £6,000.

BONKERS AND HONKERS

Helen Roycroft and her partner Nick ran the Robin Hood Half Marathon with the names 'Bonkers and Honkers' on their vests. The couple raised £1,500 in memory of Helen's mum who had MND.

10K A DAY

Duncan Bawler took on our Run 31 Miles in January challenge, but as a regular gym-goer and former personal trainer, he decided to increase it to run 10K every day. Duncan raised £4,200 which he hopes will make life easier for people affected by MND.

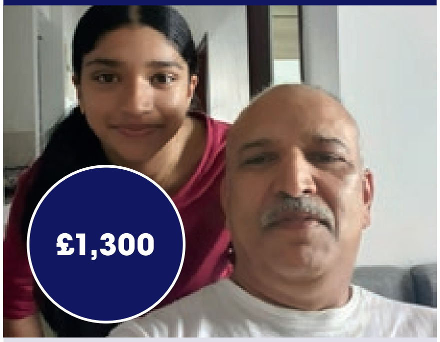
GOLF BUDDIES

Sue Pomeroy, and Ladies' Captain at Whipsnade Park Golf Club, Sade Gbago, selected the Chiltern Branch as their charity of the year. Their support resulted in the grand sum of £25,200 being presented to the local branch.

SUMMITING FOR STUART

To honour her husband Stuart's memory and raise funds for the West Sussex South Branch, Sue Acaster trekked Mount Kilimanjaro, reaching the summit on the fourth anniversary of Stuart's death. Her mountain adventure raised £1,300.

AN INDIAN FEAST



Rachel Shaji, age 16, arranged a fundraising event at her local church, Agape Christian Fellowship, in Manchester. Passionate about cooking, Rachel raised money for the charity to honour her dad, Shaji Abraham, who sadly died in January. Rachel raised £1,300.

BALANCE BALL

When Yacob had a stroke at the beginning of last September, he was given exercises to do as part of his rehabilitation. Seizing the opportunity to challenge himself, he decided he would throw a ball from hand to hand while balancing on one leg for a minute. This was a huge challenge for Yacob, but not only did he do it, he also raised £1,075 for the MND Association.

SQUATS CHALLENGE

Sue Hayward, who won a gold medal for her MND Garden at the Chelsea Flower Show in 2019, has continued to support the Association. In November, she completed the 5,000 squats challenge, raising almost £1,000 in memory of her friend who died from MND within three months of diagnosis. Sue said: "Thankfully the Association were able to help her and the family in their time of need."

DOIN' IT FOR GILLY

Gillian Gee (Dr Rees) was a GP who died from MND in September 2024. To honour her memory, more than 130 family, friends and colleagues joined the Trentham Gardens Park Run on 1 February, many of them wearing blue 'Doin' it for Gilly' MND Association t-shirts. The t-shirts raised £2,600 and Gillian's twin nephew and niece, aged 9, raised £700.

HAVE OUR STORIES ENCOURAGED YOU TO TAKE PART IN AN EVENT?

If you've been inspired to take part in a fundraising event for the Association, there are loads of ideas to make a difference at **www.mndassociation.org/fundraising**

See your copy of the Impact Report 2024 inserted with this issue
and at **www.mndassociation.org.uk/our-impact**

2024: Our year in numbers

£3.2m

of support grants awarded to **2,990 people** with or affected by MND

A RECORD-BREAKING

£40m

total income raised

FOR EVERY £1 SPENT DIRECTLY ON FUNDRAISING **£6.78 WAS RAISED**

1,500

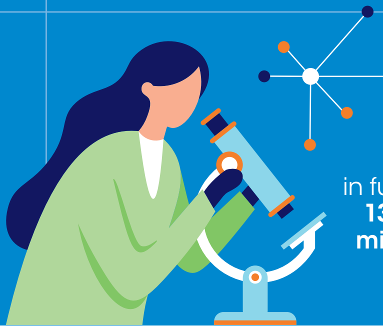
delegates from 45 countries attended our **35th International Symposium on ALS/ MND** in Canada in person and online

12,926

registered Association Members eligible to vote on the direction of our work

£3.7m

1,020 cases handled by our Welfare Benefits Service, potentially unlocking eligible claims worth £3.7 million



£24m

in funding committed to support **133 research grants, with £9.3 million** of new research funding awarded (31 December 2024)

UNLOCKING ACCESS TO TOFERSEN

Last autumn tofersen, a breakthrough drug proven to substantially slow progress of MND in people with the SOD1 genetic change, moved a step closer to being approved following our successful campaign, Prescribe Life. The campaign called on NICE to assess tofersen as a rare disease drug, rather than through its standard route, where it would most likely fail.

Following the campaign, NICE confirmed it would assess tofersen as a highly specialised technology.

While tofersen is progressing through the NICE approval process, Biogen, the pharmaceutical company behind the drug, has kept its early access programme open, so people with SOD1 MND can receive it. However, the Association has become aware a small number of people with SOD1 MND can't access it.

In response, the Association launched an urgent investigation. After speaking with specialist clinics, neurologists and people with MND, we estimate 12 people who have SOD1 MND are currently unable to access tofersen because the NHS doesn't have the capacity to deliver it.

That's because tofersen isn't an easy drug to take. Unlike a pill or injection, tofersen requires a monthly injection via lumber puncture, where a needle is inserted between the bones in the spine to deliver the drug directly into the spinal fluid. While Biogen is providing the drug for free, there are costs to the NHS, including staff training, clinic time and support staff to ensure patient safety.

Until tofersen is commissioned as an NHS treatment, clinics are offering the treatment on a 'goodwill' basis. This has resulted in a limit on the number of people who can access the drug.

The MND Association is determined to find a solution. While we are hopeful tofersen will be approved by NICE and so be available on the NHS in the future, something needs to be done now. We have engaged with Biogen and NHS England, and discussed the issue at the April meeting of the MND All-Party Parliamentary Group (APPG).

Following that meeting, the APPG has written to Karin Smyth, the minister responsible for secondary care at the Department of Health and Social Care, calling for urgent action. MND Association Chief Executive Tanya Curry has also written to the minister directly.

We will continue to push for urgent action and do all we can to ensure nobody misses out on this ground-breaking new treatment.

With more than 30 episodes available, the Association's MND Matters podcast offers a wealth of information and insight from experts and members of the MND community. Dip into the episode library at any time to hear informal advice, information and real-life experiences about a range of topics including managing emotions, family support and becoming a carer for someone with MND.

UPCOMING EPISODES:

A new age of voice banking

Five years ago we recorded our first episode about voice banking. Back then, it took around 30 minutes to bank a voice which was considered revolutionary at the time. Today, it can take as little as 30 seconds. We'll look at the advancements in voice banking technology and how Artificial Intelligence (AI) has proved transformational in this area.

Eating and drinking

MND can affect swallowing, eating and drinking, which in turn has the potential to impact on emotions, wellbeing and social activities. In our upcoming episode, our expert guest will explain what some of these changes might be and share techniques and adaptations to ensure people with MND continue to get the right nutrition in an enjoyable way.

Have you got a topic you'd like us to cover on the podcast? Email communications@mndassociation.org with your suggestion.

LISTEN ONLINE

Listen to all episodes on our website at www.mndassociation.org/mndmatters or search MND Matters wherever you get your podcasts.

FOLLOW US ON SOCIAL MEDIA

We share lots of information, advice and updates on our social media channels where you can interact with other members of the MND community and share your own experiences.

Our **Facebook** page is a thriving hub for all things MND Association. Engage with our updates and stories, sign up for fundraising events and talk to others affected by motor neurone disease.

Facebook.com/mndassociation

Over on **X, formerly Twitter**, you'll find the very latest information about research, campaigning and the support we provide.

x.com/mndassoc

As you'd expect, the MND Association's **Instagram** feed is full of inspiring pictures and videos telling the story of the MND community.

instagram.com/mndassoc

On **TikTok** you'll find everything from the latest antics of our mascot Buddy, to fundraisers showing just how inventive they can be when it comes to raising money and awareness. We get involved with some of the latest Tiktok trends too!

tiktok.com/@mndassoc

Our **LinkedIn** feed shares opportunities to engage with the charity, our collaborative efforts and recruitment updates.

linkedin.com/company/mndassociation

ABOUT US

The Motor Neurone Disease (MND) Association

We improve care and support for people with MND, their families and carers, and fund and promote research that leads to new understanding and treatments.

We also campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society. As a charity we rely on voluntary donations. Our vision is a world free from MND.

SOCIAL MEDIA

Online forum A place for people affected by MND to share experiences and support each other.
https://forum.mndassociation.org

mndassociation
mndassoc
mndassoc

MND CONNECT

Our **MNDConnect helpline** offers advice, practical and emotional support and signposting to other organisations. **Open Monday to Friday 9am to 5pm**

mndconnect
0808 802 6262
mndconnect@mndassociation.org

MEMBERSHIP

To receive a regular copy of *Thumb Print*, call **01604 611860** or email **membership@ mndassociation.org** If you would prefer to receive your copy of *Thumb Print* under plain cover please let our membership team know.

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association

Coming Soon – The MND Association Summer Raffle!

Help move us closer to a world free from MND

1st prize: **£5,000**

2nd prize: **£1,000**

3rd prize: **£500**

20 x Runner-Up prizes: **£25**

Thanks to wonderful supporters like you, our last Summer Raffle raised over £100,000! Which provided vital help to people living with MND, their families and carers, and fund research into MND.

We hope you will join in with the Summer Raffle this year!

Raffle opens 6 May 2025

Visit mnda.raffleentry.org.uk or call 0330 002 0342 to play

Closing date: 25 July 2025 **Draw date: 1 August 2025**

Don't forget you can also sell tickets to friends, family, colleagues and neighbours. Please request paper tickets over the phone or email **raffle@mndassociation.org**

Every £1 ticket you buy goes towards funding important research into effective treatments and supporting people living with and affected by MND.

T&Cs: You must be over 18 years of age to play. Entry is open to all UK residents excluding those in Northern Ireland, Jersey, Guernsey and the Isle of Man. Raffle rules are available at mnda.raffleentry.org.uk for full terms and conditions including information on prize allocation, proceeds and chances of winning.

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