mnda
motor neurone disease association
Membership

SUMMER 2025

THUMBPRINT

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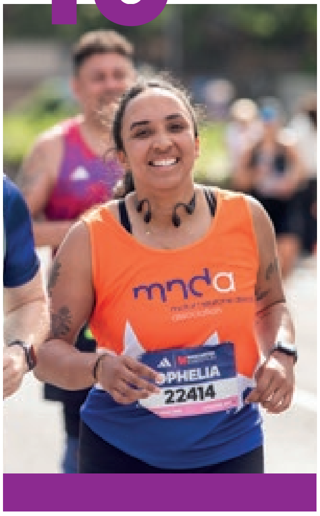

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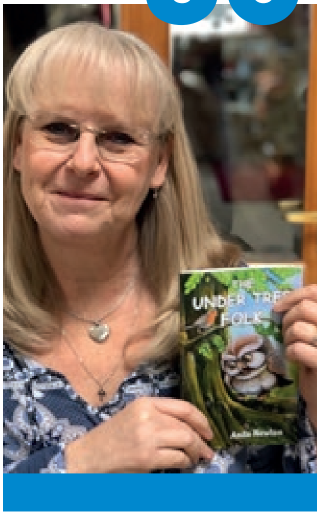

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On the cover

Mohammed Yassin who is living with MND, attending the Liverpool Roadshow in May.

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

Sometimes opportunities come along which offer a new approach and encourage a different way of thinking. By being brave and stepping out of the familiar there's the possibility of making a real change.

That's what the Longitude Prize on ALS represents to the MND Association. We are delighted to have been able to commit to being the principal funder of this innovative project, launched in June, which is setting the challenge of using artificial intelligence (AI) to transform drug discovery for the treatment of MND. The Prize is all about bringing brilliant minds from different specialisms together to collaborate in problem-solving and finding solutions. You can read more about the Prize and what it could mean for the MND community on page 23.

And that's not the only new opportunity we've embraced recently. During June, we partnered with Omaze, the company which organises the Million Pound House Draws. We're set to receive at least a million pounds from the draw to win a stunning £4 million beach front house in Sussex. As *Thumb Print* goes to press we're waiting – excitedly - to hear the total raised, with the money going directly into the ongoing development of our MND Association Research Nurse Network, directly linking people with MND with research.

Mike Willis is a great example of how getting involved with research brings hope and a sense of purpose. He spent a day in the lab thinking about riding elephants and dancing at a party – all in the name of science! You can read his firsthand experience of helping to develop tools to interpret brainwaves to support communication on page 34.

I'd like to say a big thank you to our wonderful storytellers Anna, Lee and Michele who agreed to share their personal experiences of MND through our Global MND Awareness Day campaign *Hidden Realities* – and to every one of you who felt able to do the same. Your honesty, openness and strength is, as ever, inspiring. Read more on pages 4 and 5.

And finally this issue, with summer most definitely here, I hope you find the feature on pages 20 and 21 about holidaying as a family with MND useful. Do remember we have a wide range of information available on our website and through our care information leaflets offering help and tips about everything from transport to eating to relationships. The latest updates are detailed on page 38.

Tanya

> **"Sometimes opportunities come along which offer a new approach and encourage a different way of thinking. By being brave and stepping out of the familiar there's the possibility of making a real change."**
>
> 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.

SHINING A SPOTLIGHT ON HIDDEN REALITIES

(Top right) Michele Ogden who appeared in our campaign Hidden Realities
(Left) Digital billboards featuring Anna Barrow at Trinity Leeds and (bottom right) featuring Lee Wilkinson near the Bullring, Birmingham

Behind every person living with or affected by MND there's a unique story. On Global MND Awareness Day this year we shone a spotlight on those stories and the hidden realities of the disease.

Anna Barrow, Lee Wilkinson and Michele Ogden agreed to be at the heart of our campaign, sharing their own experiences of MND with messages of defiance, refusing to be robbed of their ambition, their inner strength or the words they want to say.

Their powerful messages were displayed across billboards in cities including London, Birmingham, Newcastle and Leeds, in partnership with Ocean Outdoor, for tens of thousands of people to see in the days leading up to Global MND Awareness Day on Saturday 21 June.

Those same personal insights were also shared across our social media channels, linking to videos where the trio revealed more detail about their lives, the difficulties they face and the joy they find in every day – the hidden realities of living with such a brutal disease.

The emotional messages sparked a myriad responses from across the MND community with people opening up about their personal experiences, sharing their own hidden realities.

That when someone you love passes from MND, it's a weird mix of relief and sadness - but also anger that that's how they went 🧡 💙

That when people say they "understand" although they mean it with good intentions and love, they have absolutely no idea. And in that way, they're lucky.

The impact of loss of hope. Most other illnesses have a chance of cure.

Mims Davies MP, Shadow Secretary of State for Wales

Alan, who is living with MND and Jan, chair of the SW Wales Branch

Presentation to Senedd members and guests

Eleanor Dalley and Seckin McGuirk both living with MND, Westminster

Natasha Asghar, MS

Nearly two thirds (61%) of UK adults knew little or nothing about MND, while more than half (53%) said they had heard of MND but didn't know much about it.

What the public said

Alongside sharing the stories from people with and affected by MND, we also quizzed the general public to find out what they understand about the disease. Nearly two thirds (61%) of UK adults knew little or nothing about MND, while more than half (53%) said they had heard of MND but didn't know much about it, eight per cent had never heard of the disease.

The YouGov survey commissioned by the MND Association spoke to 2,077 people. While some people correctly identified that MND can affect speech and movement, 33% thought MND affects the sense of touch and 15% thought it caused a loss of smell.

The results, along with interviews with Association representatives, were published in media outlets including newspapers, radio stations and online.

Chief Executive of the MND Association Tanya Curry said: "Our survey shows awareness of MND and its devastating effects is far too low. We owe it to all the people living with the disease to make more people aware of the immense challenge MND brings to the realities people face every day."

Awareness events

We marked Global MND Awareness Day at Westminster and the Welsh parliament, hosting drop in events for Members of Parliament and Members of the Senedd to find out more about our work. People with and affected by MND travelled from across the nations to highlight campaigning asks to Members, including access to new treatments, genetic testing, cost of living and better support for unpaid carers.

And a number of Association branches and groups marked the special day in the global calendar by arranging for local landmarks to be lit up in blue and orange. The photos were shared across social media.

On Global MND Awareness Day eve, Gloucestershire Cricket Club turned Pink 4 Syd, in honour of former England cricketer David 'Syd' Lawrence, who was diagnosed with MND a year ago. All profits from the game were donated to the MND Association. The game took on an extra poignancy when it was announced that Syd, who was awarded an MBE in the King's Birthday Honours in June, died the day after.

33%

thought MND affects the sense of touch.

15%

thought it caused a loss of smell.

CONNECTING WITH OUR COMMUNITY

"There was so much positive energy in the room at these events, driven by the dedication and commitment of our wonderful volunteers. Their brilliant thoughts, insightful suggestions and informed questions were at once inspiring and thought-provoking."

Tanya Curry, Chief Executive

"We must work with our community to help shape our work."

These were the words of the MND Association's Chief Executive, Tanya Curry as the first of our Regional Roadshows for 2025 came to a close in Liverpool in May. Following on from last year's successful events, our roadshows this year were an opportunity for volunteers and members of the MND community to hear from Tanya and our Executive Leadership Team about our priorities for the next five years.

Key priorities

Members of the Leadership Team delivered a series of talks covering the Association's priorities and our strategic goals focused on achieving our vision of a world free from MND.

Presentations covered our income growth, our Omaze partnership (which you can read more about on page six), our planned and targeted campaigns programme and our research priorities, including improving our approach to involving people with MND in research.

Our volunteering network was put under the spotlight with a thank you shared to everyone who supports the Association's work by fundraising, running support groups and supporting people with MND.

Roundtable sessions with attendees – including people with and affected by MND, volunteers and supporters - led to lively discussions on the research innovations they would like to see over the next five years. And there was a chance to share ideas for how we can all work together to support our community.

Debbie Williams, Wirral Group chair

Alun Owen, Merseyside Branch Chair said of the Liverpool Roadshow: "I was looking forward to finding out the Association's plans for the future and I wasn't disappointed! The day was well-organised and structured and information-packed with excellent presentations from Tanya and the directors. As a long-standing volunteer for the Association, it was very pleasing to learn of the success of the efforts to raise awareness of MND and the positive impact this means for people living with the disease.

"The regular breaks built into the programme also gave a great opportunity to catch up with old friends and meet people who will now be new friends! I left the day feeling very energised and positive about the work of the Association."

Babs Williamson, volunteer at the Wirral Group said: "It was a very useful day, well led with the right depth of information given. The research presentation gave good insight into current developments and staff members were fully engaged and led the roundtable sessions well. I'm glad I attended!"

Wirral Group chair, Debbie Williams (pictured left) added: "Understanding the plans for the future and involving the volunteers in discussions will help us deliver these changes at a local level."

A montage of images from the Liverpool Regional Roadshow in May

'EVERY DAY YOU'RE WAITING, YOU'RE LOSING SOMETHING'

Seckin McGuirk, 56, is one of a dozen people who are being denied tofersen, the first effective MND treatment to be identified for decades. Seckin was diagnosed with MND in June 2024, and later found out that she had the SOD1 gene which can be inherited by family members.

For the retired maths teacher from Rugby, it is impossible to understand why she is not able to have the treatment. Seckin said: "I just struggle to comprehend if such a drug is available, and just because there is no staff to deliver that drug, they can't take patients in. It is not many people.

"It's such a terrible illness, it feels like every day there is something going away from you. Every day you're waiting, you're losing something."

Tofersen has been shown to slow, and in some cases halt, progression of symptoms in people living with a form of MND caused by a variation in the SOD1 gene.

Currently over 30 people with SOD1 MND are receiving tofersen through an Early Access Programme (EAP) supported by Biogen, the developer of the drug. However, the MND Association believes 12 people are being refused access, despite having the same level of need.

Biogen provides tofersen free but, because it is not yet a commissioned treatment, capacity to deliver the EAP is provided on a 'goodwill' basis.

The MND Association has learned that many of the care centres and networks where it provides funding have been advised they cannot accept any more people onto the EAP.

The MND Association's *Prescribe Life* campaign is calling on the Government to take urgent action so everyone who needs tofersen can access the EAP.

Tanya Curry, Chief Executive of the MND Association, said: "People with MND don't have time to wait and a solution is desperately needed to break down the barriers to access – and it is needed now."

Visit our website to find a petition addressed to Karin Smyth MP, Minister of State at the Department of Health and Social Care. It calls on the minister to intervene immediately and help ensure that nobody misses out on this vital treatment.

Prescribe Life

Seckin McGuirk

Prescribe Life **petition hits**

20,900

signatures!

SHORTLISTED 2025 PURPOSE AWARDS

PRESCRIBE LIFE CAMPAIGN SHORTLISTED FOR PURPOSE AWARD

Our original *Prescribe Life* campaign was shortlisted for Best Advocacy Campaign at this year's Purpose Awards, with the ceremony held on Friday 6 June.

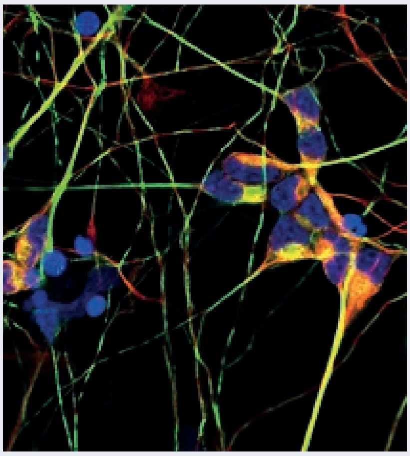
Run in partnership with Texture and Torchbox, the campaign urged NICE to reconsider its decision on tofersen, a vital treatment for people with SOD1 MND. In just three weeks, over 15,000 supporters signed our petition, prompting NICE to announce a reappraisal of its decision.

Although we didn't take home the award, it was an incredible honour to be named a finalist among such inspiring campaigns.

MEET THE RESEARCHER – DR HAMISH CRERAR

Dr Hamish Crerar of University College London and the Francis Crick Institute, is one of the MND Association's Non-Clinical Fellows.

His work is focused on understanding how tiny molecules inside our cells, called RNA, go wrong in people with MND. These molecules are like messages that tell our cells what to do. In MND, these messages often get mixed up. Understanding why could help point towards a treatment. Here, Dr Crerar explains more.



Electron microscope image of a human stem cell

I've always been fascinated by how our nervous system works – how it grows, develops, and sometimes, sadly, how it starts to break down. I love the idea that I can take that fascination and turn it into something that might actually help people.

If we can figure out exactly what's going wrong inside nerve cells in MND, we might be able to find new ways to treat it – or stop it from getting worse. It's a small piece of a big puzzle, but every new discovery gets us closer to better treatments or even a cure.

On any typical day I work with stem cells – cells that can turn into other types of cells, like nerve cells. They need a lot of looking after and I feed them the right nutrients, keep them warm, make sure they're healthy. Once they've turned into nerve cells, I study what's going on inside them.

Sometimes you discover something no one else in the world has ever seen before. One new and perhaps tiny discovery about cells in a lab could be the start of a breakthrough that helps people in the future. That's an amazing feeling.

To unwind, I've done a few triathlons and bike races, but most of my time outside work is now spent with my two young children – they're my main passion now!

> **"It's so rewarding knowing the work you're doing might one day help someone live longer or have a better quality of life. It's a great feeling to be part of a team that's working to solve a really tough problem."**
>
> Dr Hamish Crerar

RECORD INVESTMENT IN MND RESEARCH

The MND Association has announced a record level of research investment, underlining its ongoing commitment to funding world-class studies that drive forward the knowledge and treatment of MND.

As of 31 May 2025, the Association's research grants portfolio includes 138 grants, with a combined value of £26.9 million. This marks a significant rise from December 2024, when 133 grants were valued at £24.2 million, and an even greater increase from almost £21.5 million just a year ago.

This growing investment is supporting an expanding network of researchers. Around 320 clinicians and researchers are involved in MND Association-funded projects. Of these, approximately 80 are early career researchers. Funding these emerging researchers enables them to focus their careers on MND, supporting the next generation of research leaders. This is vital in order to build long term research capacity in MND research.

Mike Rogers, Director of Research and Innovation at the MND Association said: "MND is now one of the fastest moving fields of neurological disease research.

"Thanks to the dedication of our supporters and the wider MND community, we are the leading charitable funder of MND research in the UK and are able to continue our commitment to not just funding outstanding science, but to building the research infrastructure that allows innovation to flourish.

"By encouraging collaboration, supporting talented researchers at all career stages and focusing on translating discoveries into treatments, we are driving real momentum towards breakthroughs that people living with MND so urgently need."

Mike Rogers, Director of Research and Innovation at the MND Association

The current portfolio also includes ten newly approved project grants, due to start in the coming months, along with a range of studentships starting in autumn 2025.

MIROCALS TRIAL RESULTS PUBLISHED

The results of the MIROCALS clinical trial into the effects of low dose interleukin-2 (IL-2) on people with MND were published in The Lancet early in May.

While some of the results seem promising, they are complex. Overall, the data suggests IL-2 is not an effective treatment for all people with MND although it may have a benefit for people with MND who have slower disease progression.

Since publication, the UK MND Clinical Studies Group, made up of leading neurologists and researchers, has shared a statement which says: "The trial is an important step forward... More data [is] urgently required to give a definitive answer on the potential therapeutic benefits of IL-2. The most thorough route to gather [this] is a comprehensive phase 3 trial which would likely be led by the pharmaceutical industry. An alternative or complementary approach would be an early access scheme."

The MND Association has since been in discussions with ILTOO Pharma, the pharmaceutical company which has the commercial agreement to use the trial data and also the company which manufactured the drug used in the trial. Those discussions are ongoing with our focus remaining on doing everything we can, in collaboration with other MND charities, to ensure people with MND have equitable access to proven treatments as quickly as possible.

Further updates will be shared on our website and in future issues of *Thumb Print*.

The MIROCALS study received funding from the MND Association supported by the J P Moulton Charitable Foundation and the Garfield Weston Foundation.

FUNDING BOOST FOR AI POWERED RESEARCH PROJECT

A cutting-edge research project using artificial intelligence (AI) to improve the safety of new therapeutics for people with MND has secured funding from Rosetrees, a private medical research charity, and the MND Association.

The two charities have come together to jointly fund a Lady Edith Wolfson Rosetrees Non-Clinical Fellowship, awarded to Dr Oscar Wilkins at University College London. Dr Wilkins will lead a £330,000 project called *Improving the safety and specificity of the TDP-REG system for MND research and gene therapies*.

This project aims to activate treatments specifically in diseased cells, significantly reducing potential side effects elsewhere in the brain and body. By using AI to help design therapeutics which 'hack' disease processes in the cell, Dr Wilkins will be able to activate therapies only where it is needed.

The research could dramatically improve the safety and effectiveness of gene therapies in pre-clinical studies, potentially accelerating the development of safer treatments for people living with MND.

Vineeth Rajkumar PhD, Head of Research at Rosetrees said: "Through our collaboration with the MND Association, we're proud to support this exciting early career fellowship. We are committed to investing in early career researchers and providing the support they need to help them transform our understanding and treatment of MND."

The MND Association's Chief Scientist, Dr Brian Dickie said: "The Rosetrees Foundation has a longstanding record of supporting the progress of innovative science from the lab to the clinic. We're delighted to partner with them to support this exciting research, led by an outstanding young researcher."

Rosetrees
Supports the best medical research

Dr Oscar Wilkins

For more information about the research we fund, visit www.mndassociation.org/research-we-fund

OMAZE PARTNERSHIP TO FUEL NEW MND RESEARCH

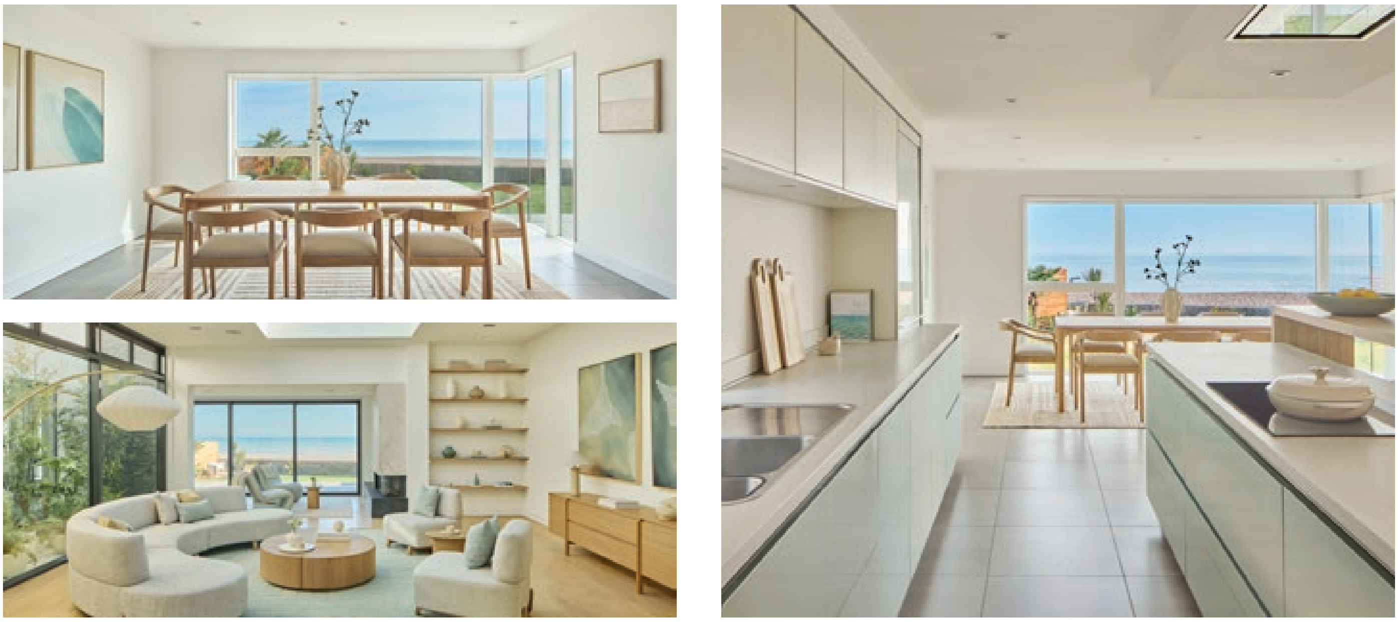
MND Association patron, Eddie Redmayne

High-profile supporters including Oscar-winning actor Eddie Redmayne OBE, rugby legend Kevin Sinfield CBE, actor Lily James, journalist JJ Anisiobi, *Coronation Street's* Daniel Brocklebank and *The Chase's* Shaun Wallace all played played a leading role in a partnership which promises to fuel progress in MND research.

Association patrons, Eddie and Kevin, together with ambassadors, Daniel and JJ and Branch Patron Lily James, all helped to spread the word about the Association's exciting partnership with the Omaze Million Pound House Draw which officially launched in May. Eddie fronted the campaign's television and digital adverts, JJ wrote a special article for the Daily Express while Kevin, Lily, Shaun and Daniel all created videos on social media, sharing their own experiences of MND to promote the partnership and the difference the money raised will make to our community.

As well as giving one lucky winner the chance to change their life by winning a beautiful beachfront home in Sussex along with £250,000 in cash,

A well-equipped outdoor kitchen is also included in the prize



Above: Sussex beachfront home fully furnished with contemporary styling

the draw promised to revolutionise the fight against MND with a minimum of £1 million being donated to help fund the Association's pioneering Research Nurse Network. The project will streamline the clinical trials process, allowing people living with MND to get involved much more quickly while accelerating progress towards the development of potential new treatments.

The MND Association's Chief Executive, Tanya Curry said: "We are so grateful to Omaze for supporting our vital work, investing in cutting-edge research and supporting people with MND.

"The funds this partnership raises will support the ongoing development of our Research Nurse Network. This nationwide team of specialist nurses will empower people, giving everyone diagnosed with MND the choice to take part in potentially life-saving clinical trials, and so speeding up life-saving research."

The name of the winner, together with the amount raised on behalf of the Association from the appeal have remained a closely guarded secret but were announced as *Thumb Print* went to press. We'll be sharing more news about the transformative impact this partnership will have on our work in the next issue.

Here's just a selection of reactions to the Omaze partnership on social media...

MND helped us through losing both my mum a few years ago and just recently my brother to this awful disease 💗💙xxx

I am already a subscriber to the Omaze draws, so to hear that they have partnered with MND is amazing news.

I've got MND and I play this everytime ❤️💙🧡 well done OMAZE.

So pleased the charity has been chosen. We need all the awareness and funding we can to find a cure, or at the very least an effective treatment, as we have neither at this time.

Brilliant news, we have been in these draws for sometime now and glad to donate to such a wonderful charity that have helped and continue to help our family 🫶🤞🤞🤞🤞x

There isn't a more worthy cause! MND it's truly the most horrible disease !!!

HONOURED FOR DEDICATION TO MND SUPPORT

Chris Allen, a retired electrical engineer from North Wales, has been honoured with the High Sheriff of Clwyd's Award for his remarkable contribution to the community through volunteering with the MND Association.

Chris began his journey in 2005 when his wife, Brenda, was diagnosed with MND aged just 44. "The diagnosis was devastating," he recalled. "But we changed our attitude overnight. We stopped worrying about things we couldn't control and started making memories."

Brenda died two and a half years later, but her courage inspired Chris to give back. He's been volunteering ever since - initially with his local North East Wales Branch and now as an Association visitor. "To me, it's about giving something back for the help we received as a family," Chris said. "You can't put a figure on a person's time."

Over the years, Chris has provided support to people with MND and their families across North Wales. He said: "People with MND are the bravest I've ever met. There's only one outcome - it's just a matter of when - but they still fight every day."

The award came as a surprise for Chris. "I didn't even know I'd won until I saw my name in the programme," he said. A further highlight was when someone approached Chris to say he had supported their dad. Chris said: "That meant a lot. You don't always realise the impact you've had."

For Chris, volunteering isn't about awards. He said: "It's about being there - listening, supporting, making even a small difference."

Chris, Brenda and their two sons on holiday

High Sheriff of Clwyd award

HOW CHANGES IN GENES CAN AFFECT MND

Genes carry information that control our characteristics - from our hair colour to our height, to the risk of developing certain conditions. Genes contain instructions to make proteins which are needed for our bodies to function as they should.

People with MND can have changes in their genes which play a role in the disease. This might be too much or too little of a protein is produced, or a faulty protein is made. This can cause damage to motor neurones and other cells.

There are changes in many different genes that are linked to MND, including SOD1, C9orf72, FUS and TARDBP. It's likely there are some genes with changes linked to MND which have not been identified yet. The MND Association is currently funding 26 projects looking at the role of genes and proteins in MND and ten investigating gene therapies.

While lots of gene changes have been linked to problems with motor neurones, one project led by Dr Johnathan Cooper-Knock at the University of Sheffield is looking for new gene changes in other types of brain cells which support motor neurones, hoping to identify new targets for treatments.

Gene therapies are a type of treatment which aims to fix or replace a changed gene, so it will either no longer produce faulty versions of the protein, or produce more of the healthy version of the protein.

One researcher looking into gene therapies is Dr Oscar Wilkins, who is funded by the MND Association through the Lady Edith Wolfson Fellowship (also featured on page 11). His study, based at University College London, is researching new methods of delivering gene therapies, hoping to make them safer, and only active in cells affected by the disease. These promising new developments could enable gene therapies to be delivered to people with MND in the future in a safer and more effective way.

Find out more about the research we fund by visiting www.mndassociation.org/research-we-fund

Dr Oscar Wilkins

Dr Johnathan Cooper-Knock

CELEBRATING OUR AMAZING VOLUNTEERS

VOLUNTEERS' WEEK

Volunteers' Week, which is held between

2-8 June

is an annual opportunity for organisations like the MND Association to celebrate the incredible work of our volunteers across England, Wales and Northern Ireland.

VOLUNTEERS' WEEK

PROVIDING SUPPORT

The MND community continues to be supported by volunteers, with

135 support groups

providing a safe space to meet and talk, many run solely by volunteers.

FUNDRAISING

During 2024, our **87 branches and groups** provided information, companionship and support, and

raised £3.5 million

to support the Association's work.

ONE-TO-ONE SUPPORT

Last year, **1,200 people with MND** received one-to-one support from our

312 trained Association visitors

Diana Keys, a recently-retired school administrator who is living with MND, said: "I have an Association visitor and she's just the best... I can explore things with her before taking them to my family. She'll take the worry away and make phone calls for me, because I struggle with my voice."

From committee members and treasurers, to campaign volunteers and social media officers, to Association visitors and our amazing MND support groups – THANK YOU!

ICYMI

IN CASE YOU MISSED IT!

Our fortnightly newsletter for volunteers, The News, features inspiring stories of fundraising and community support from across our volunteering network. In case you missed them, here are just a couple of the stories featured recently:

CUPPA AND CATCH UP

In Cardiff, regular 'Cuppa and Catch Up' sessions have proven to be popular after the Cardiff and Vale of Glamorgan Branch reached out to people affected by MND in the area. Branch chair, Kate Bryon said of the latest session earlier this month: "Lots of new people came along and it was great to see everyone chatting, sharing their experiences and exchanging numbers."

BIRTHDAY CELEBRATIONS

Our West Sussex South Branch turned 40 in May and is celebrating this special anniversary throughout 2025. The branch's supporters are taking on various challenges to mark the milestone, including several members who took part in a 40-mile walk over seven days in May!

MARATHON effort for #TeamMND

Marathon season has got off to a flying start with the Association's incredible runners braving the spring heat to raise more than £1 million.

In Brighton, 75 runners took part in the event raising £114,000 to support the Association's work.

Among them was former *Gogglebox* star Daniel Lustig who took part in his first marathon on behalf of the MND Association in memory of his friend Kelly, who died from MND shortly before her 40th birthday. He was running as a member of LGBTQIA+ running group, Brighton Front Runners.

He said: "When I shared on Instagram that I was doing the Brighton Marathon for the MND Association, I had so many messages. So many people got in touch to share their stories of loved ones who'd been touched by MND. It was lovely that so many people reached out having been affected.

"Kelly was the most genuine, kind-hearted person you could ever meet. She was such a brilliant character, and an amazing friend. She would have thought I was crazy for running a marathon. I don't think she ever went to the gym in her whole life! But she'd have had a glass of champagne waiting for me at the end!"

Endless blue skies and soaring temperatures welcomed #TeamMND runners to Manchester and London, making for challenging conditions on the courses. More than 300 people took part in both events raising more than £629,000.

#TeamMND cheer squads lined both routes with the Association's South London Branch out in force at mile 21 in London, while volunteers from the Manchester and District Branch handed out sweets and plenty of cheers and encouragement at mile 21 in Manchester.

In London, MND Association patron Charlotte Hawkins was there to cheer on everyone taking part, including her husband Mark. He was running his first marathon on behalf of the Association in memory of Charlotte's father Frank, who died from MND.

Over £1M raised!

The sun also shone on Leeds for the Rob Burrow Leeds Marathon on Sunday 11 May, which saw the MND community come together to remember Association patron, Rob Burrow CBE who died from MND in June last year.

More than 1,100 runners chose to run the half marathon and marathon in support of the MND Association. They braved sweltering conditions to raise more than £550,000. Thousands of people brought the city to a standstill to cheer all the runners round the course and show their support for the MND community.

Main picture and far right, Manchester Marathon

Damian Dexter, from youth rugby club Weatherby Bulldogs explained he was taking part having been supported by both Rob and his former teammate Kevin Sinfield CBE in the past. He said taking part in the marathon had been his way of giving back to the community.

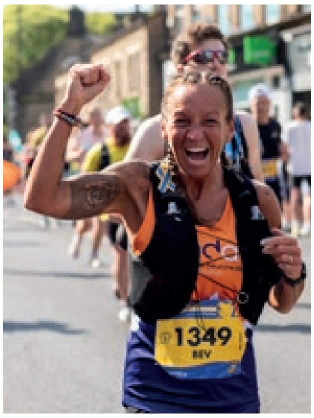
He said: "The rugby league community is very special indeed, words just can't describe what it feels like to be here. What Rob and Kev have done to raise awareness of MND is just incredible."

The MND Association's Director of Income Generation, Jo Coker said: "Over the past few weeks the strength of the MND community's team spirit has really shone through with our incredible runners taking on extraordinary challenges in difficult conditions."

> **"We are so grateful to all our runners for their dedication and commitment and for the countless hours of training it takes just to get the start line. To raise more than £1million is just incredible and will allow us to go even further in the fight against MND. Thank you so much for your support."**
>
> Jo Coker, Director of Income Generation

Daniel Lustig and right, runners at the finish line, Brighton Marathon

#TeamMND



Taking part in Rob Burrow Leeds Marathon

HIGHLIGHTING THE HEALTH OF CARERS

Left: Martyn Barrow on the BBC Breakfast sofa talking to Jon Kay and Sally Nugent about caring for his wife, Anna. Centre: Jackie Wilson with daughter Jenn. Right; Marcia and her husband Shawn

Research, released during Carers Week in June, showed that 43% of current or former carers – an estimated 10.7 million people – have seen a mental or physical health condition develop or become worse since taking on a caring responsibility.

Led by Carers UK and supported by the MND Association and other charities, Carers Week aims to raise awareness and highlight the challenges unpaid carers face, while recognising the contribution they make to families throughout the UK. This year there was a focus on the enormous toll caring can have on an individual's health and wellbeing.

During the week, MND carers Jackie and Marcia shared their experiences of caring across our social media channels, while carer Martyn Barrow appeared on the BBC *Breakfast* sofa to talk about caring for his wife Anna, who was diagnosed with MND in 2023.

Martyn said: "Every decision I make nowadays has Anna at the forefront of my mind. If I ever want to go out and do anything I have to think to myself 'is it ok, can I leave Anna for half an hour?' It's not about someone saying 'go and have a day on your own', as that gives me more anxiety being away from Anna."

The emotional toll of caring is also shared by Craig Pollard, who cares for his husband Alex Herd.

Craig said: "I'd say caring for Alex has been more of a marathon than a sprint. I've learned that neglecting myself to focus solely on Alex wasn't sustainable. It led to health issues for me, and I've had to adjust. It felt isolating. Giving up social elements of life, like friends and work, added to that isolation. It can be disheartening to engage with the system and feel like the political and social support is insufficient, especially when the government is relying on love and familial support to fill the gaps."

Sally Hughes, Director of Services and Partnerships at the MND Association, said: "Whether it's caring for a loved one, a friend or a neighbour, a carer's dedication often goes unseen, but it should never go unappreciated. We stand in solidarity with MND carers who give so much of themselves to support others, and we must continue to press for better support and recognition for them and the invaluable commitment they make."

Visit our support for carers webpage to find information, guidance and support for unpaid or family carers of people with MND or Kennedy's disease.

> **"We stand in solidarity with MND carers who give so much of themselves to support others."**
>
> Sally Hughes, Director of Services and Partnerships

Sally Hughes, Director of Services and Partnerships

"I'M STILL HERE AND I'M STILL ABLE TO DO MY JOB"

> **"I see my colleagues as my work family... They're going to tick all the boxes around sickness and procedures, but at the same time, they're compassionate, and they have just been such great support."**
>
> Lorraine Redmond, who is living with MND

As a self-proclaimed social butterfly with a passion for helping others, for Lorraine Redmond, staying in work after her MND diagnosis was vital - not just for financial stability, but for her sense of identity and wellbeing. Fortunately, her employer's unwavering support has allowed her to continue doing the job she loves.

"When I was diagnosed with MND – apart from telling my family – my immediate thought was about my job," Lorraine shared. "Are they going to help me? What are they going to do? Are they going to force me into early retirement?"

Those fears were quickly alleviated by the compassionate response of her colleagues and managers at Croydon Council, where Lorraine is a Service Manager for Early Help Localities. "I see my colleagues as my work family," she said. "They're going to tick all the boxes around sickness and procedures, but at the same time, they're compassionate, and they have just been such great support."

Her employer made meaningful adjustments, from ergonomic equipment and height-adjustable desks to referrals for occupational health and therapy. Lorraine said: "They've been really supportive, willing to put adaptations in for me to continue working comfortably, both in the office and at home.

"Their support has meant everything to me. My body might be fading, but my brain is still ticking. I'm still here, and I'm still able to do my job."

Beyond practical help, her team's belief in her has had a powerful emotional impact. She said: "It makes me feel good, that they're confident in me and trust me to still make the right decisions for the service. It makes me forget about the disease. I know that it's there, I know my life has changed, and I know I now have a disability, but actually, the way they accommodate me distracts me from the disease."

HOLIDAYS AND TRAVEL WITH MND

Alex Herd, who is living with MND, and his husband Craig Pollard relax in the pool of their accessible Greek villa

Living with MND doesn't mean giving up on travel. With a little bit of planning, many people with MND can still enjoy holidays and short breaks.

Taking time away, whether for a day trip or a longer holiday can boost mental and physical health. Travel offers more than just a change of scenery. It creates space to relax, connect with loved ones and rediscover joy in life's small pleasures.

For Diane Chisholm who is living with MND and her husband Ben, holidays are more vital now than ever. Diane said: "Going on holiday takes my mind off MND. The heat helps my muscles while the rib-hurting laughter helps my mental health."

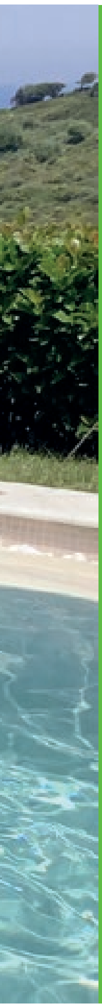
Recently Diane and Ben returned from their seventh trip to Rhodes, but it was the first time she needed to use accessibility services at the airport and the hotel. Diane said: "We booked an accessible room with lots of space for my wheelchair. The accessibility service at Leeds Bradford Airport and at Rhodes Airport were brilliant. The staff were patient and made sure I was comfortable. We are already booking our next trip. MND has taken so much from us but we will continue to do whatever we can to make the best of life."

While holidaying with MND may require more research and preparation, there are a wide variety of accessible accommodation options. Richard Offor understands the importance of thoughtful design better than most. After a life-changing spinal injury from a paragliding accident, he built Mid Wales Lodges, three luxury lodges in Llandrindod Wells, Wales.

Richard said: "Life isn't set up for disabled people. I fell 500 feet and was paralysed from the waist down. I realised very quickly how hard it is to find places that truly work when you're disabled. So I built them.

"I wanted to create a home away from home for disabled people with equipment like profile beds, riser recliners, shower chairs and Zimmer frames.

"To anyone considering a holiday I'd really recommend a site visit if you can, or if not ask to see a film of the room and any equipment available. It is also good to have an understanding of the surrounding area with a list of accessible pubs, cafes and an idea of the terrain.



Diane Chisholm and her husband Ben

> **“Going on holiday takes my mind off MND. The heat helps my muscles while the rib-hurting laughter helps my mental health.”**
>
> Diane Chisholm

THINGS TO CONSIDER WHEN PLANNING A HOLIDAY

- Plan your journey door-to-door. Think about parking, rest stops, toilets and eating.
- Airport assistance can be pre-booked and arranged free of charge. You can have help from arrival at the airport to boarding the plan.
- Ensure your accommodation meets your needs and check there is space for a wheelchair, as well as equipment you rely on at home, for instance bed rails, room hoists, walk-in shower rooms and wheel-in shower chairs.
- A cruise can be a practical choice, with all facilities in one place and you can visit several destinations while only unpacking once!
- Plan activities during times when you have the most energy and build in plenty of rest periods.

You can find more information in our Getting around and Making the most of life booklets. Search for our resources with our care information finder at: www.mndassociation.org/careinfofinder or order printed copies of resources from our MND Connect helpline: 0808 802 6262 mndconnect@mndassociation.org

“My other recommendation is to make sure you have cancellation insurance. MND can be unpredictable, so it helps to provide peace of mind in case you are not able to go.”

Alex Herd was diagnosed with MND in 2021, aged 30. Alex and his partner Craig are determined to make the most of the time they have together. On a recent holiday to Skiathos, a Greek island, Alex and Craig stayed in an accessible villa equipped with a pool hoist, allowing Alex to swim again for the first time since his diagnosis.

Alex said: “I can’t even describe how good it felt. The sensation of weightlessness, being in the water, floating – it gave me this brief return to freedom. We used floats, and I could still kick and move around. It was amazing.”

Alex admits that travel takes more energy now. He said: “My capacity for stress is a lot lower. I get overwhelmed easily, so planning carefully and focusing on one thing at a time helps. But these experiences give me something to look forward to. That alone makes it worth it.”

Prior checks about accommodation facilities and equipment ensures peace of mind when planning a holiday

> **“I realised very quickly how hard it is to find places that truly work when you’re disabled. So I built them.”**
>
> Richard Offor

VOICES OF HOPE RAISE £15,000

The voices of people living with and affected by MND were heard at a special concert held in Wiltshire.

Organised by Mel Upton, a volunteer for the North Wiltshire Group of the MND Association and the founder of Shine Theatre Group, the Love Inside Concert featured the Voices of Hope choir, which is made up of people with their own personal experiences of MND.

The performance, which was held at Ellendune Community Centre in April, raised more than £15,000.

Mel said: "There were 32 people in the choir, many of whom have been affected by MND. Among them was Adam Jones playing guitar and singing. Adam recently lost his wife Liz to MND and he performed a very moving tribute to her on the night.

"While it was an emotional evening, it was an uplifting one too. The finale was written by my daughter Milly and I, and features the thoughts and feelings of people from our community. It was very special."

The MND Association's Relationship Fundraiser, Luke Robson, who supported the choir as they prepared for the performance said: "It was wonderful to see the MND community being represented in this way.

"We are so grateful to Mel, Milly, the choir and everyone else who has been involved, for the many hours they have put in to prepare for the concert which helped us to raise awareness of this devastating disease.

"At the same time, the money raised will help us reach many more people affected by MND ensuring they get access to the care and support they need, while also funding vital research."

Members of the Voices of Hope choir

TRANSFORMING MND RESEARCH WITH ARTIFICIAL INTELLIGENCE

Pictures taken at the launch of the Longitude Prize on ALS held in June

Teams of experts and innovators from across the globe are joining forces and combining expertise to accelerate drug discovery for ALS, the most common form of MND.

Principally funded by the MND Association, the Longitude Prize on ALS is a new £7.5 million global challenge designed to spark fresh ideas and fast-track MND research using the power of artificial intelligence (AI).

Open for entries until 3 December 2025, the Prize will initially award 20 teams £100,000 each in early 2026, with one team going on to win £1 million.

Beyond financial reward, successful applicants will gain access to the largest and most comprehensive collections of ALS patient data of its kind, which combine multiple types of biological information. This helps address a major challenge in MND research, where data is often fragmented and difficult to access due to differing formats and restrictions.

Seeking innovators from across medical research, biotech, techbio, pharmaceuticals and AI, the Prize will support the most promising applications which show strong potential in both their proposed methodology and team make-up.

The launch of the Prize was marked with a special event in June, attended by more than 200 people. Speakers included Lucy Hawking, journalist and daughter of the Association's late patron, Professor Stephen Hawking, Chair of the Longitude Committee and Astronomer Royal Lord Martin Rees and our Chair Dr Usman Khan.

Dr Mike Rogers, Director of Research and Innovation at the Association and Tris Dyson, Managing Director of Challenge Works, who himself is living with MND, were interviewed by a number of media outlets including *BBC Breakfast* on the day of the launch.

Mike said: "There are many different approaches to drug discovery and development, and as the biggest charity funder of MND research in the UK, it's important we're working on a number of fronts to maximise our chances of finding effective treatments for MND.

"The Longitude Prize on ALS is exciting for a number of reasons – the international scope of the Prize, the prospect of new talented people getting involved in MND research for the first time and bringing together existing MND data from different sources across the world to increase the chance of finding something transformative for the MND community."

For more information, scan the QR code, listen to episode 35 of our podcast, MND Matters, or visit www.mndassociation.org/longitude-prize-als

CREATING PRECIOUS MOMENTS FOR CHILDREN AND YOUNG PEOPLE

Leila Connolly was just 17 when her mum told her she had MND. At the time, she was backpacking in Australia, her first trip away from home. Leila's mum told her she was to continue with her trip and enjoy every moment. Thousands of miles away from her family, Leila found strength in the outdoors.

Walking, climbing and surfing became more than hobbies, they became essential tools for coping. She said: "I started surfing while Mum was ill. It was cold, brutal and freeing. I'd come out of the water utterly exhausted and exhilarated. Nature helped me more than anything."

Nature continued to be a place of healing for Leila when she returned to England. "I left the UK as a daughter and returned as a carer," she recalls. "Mum was my best friend, a single parent and we were always so close."

Balancing three night shifts a week at a nursing home with caring for her mum at home was hard. Leila said: "I hardly slept. Fortunately, I wasn't caring for Mum alone. My stepdad was Mum's main carer. There's a unique kind of frustration that comes from being exhausted and trying to communicate through something like an alphabet board – following someone's eyes, letter by letter, just to form a single word. And when you're tired and hungry and emotionally drained, it can feel like too much.

"You're losing the person slowly – speech, mobility, independence. I was watching my mum disappear. Spending whatever time I could outside kept me balanced and well. It was my meditation; my expression; my rage; my healing."

Now 45, Leila works as an outdoor activity development officer for the National Outdoor Partnership in Wales. Having seen first-hand the importance of spending time outside, she works closely with the MND Association to provide young carers with memory-making moments.

Pictured above: Leila, kayaking
Below: Young people affected by MND on an outdoor activity challenge

Recently she organised a weekend of activities for a 13-year-old girl whose mum has MND. She said: "Hearing her mum's slurred speech triggered something deep in me, something I hadn't felt in years. She wanted her daughter to have memories, just like my mum wanted for me.

"It's so important for young carers to connect with others. Back when Mum was ill, I didn't know anyone else like me. I just felt alone.

"Being a young carer means you lose a lot, more than I can list. But you also gain. I became resilient. The outdoors gave me a place to process it all, and now I want to share that with others."

Having seen first-hand the importance of spending time outside, Leila works closely with the MND Association to provide young carers with memory-making moments.

FUNDRAISERS MAKE A SPLASH

RAISING MORE THAN £161,000

MND Association fundraisers made a real splash in May raising more than £161,000 as part of our swim challenge.

Among them was Alan Thomson, who was diagnosed with MND during lockdown in 2020. He swam 400m in May assisted by his wife Michele and the team at Sandville Self Help Foundation in Bridgend.

Alan regularly attends sessions at the Foundation's pool, something which Michele says has helped to improve both his physical and mental wellbeing. She said: "We're all so proud of him and how much he's achieved.

"Thanks to the incredible team in Bridgend, who do so much to support people with life altering and life-limiting conditions, he has been able to take part in the challenge which he was absolutely determined to do. The amount he has raised is just incredible."

Alan was diagnosed with MND after seeing former rugby league hero Doddie Weir MBE talking about his own diagnosis on TV. Having developed a limp and experienced weakness in his right hand he recognised his symptoms were similar to Doddie's and approached his GP for help. He was eventually diagnosed with MND in September 2020.

More than 900 members of #TeamMND took part in May's swim challenge, raising more than £130,000 to support the Association's work across England, Wales and Northern Ireland.

For the rest of the year, the calendar is full of more great challenges to get involved with including 15,000 steps a day in August and a 75-mile dog walk in October.

Alan Thompson

For more information, or to sign up, visit www.mndassociation.org/facebookchallenges or scan the QR code

BEST PRACTICE MND CARE IN A SHIFTING LANDSCAPE

An important opportunity for informed debate

Last month, 150 people - including Care Centre co-ordinators and directors, neurologists and other members of multidisciplinary care teams - came together in Leicestershire for our 2025 MND Care Centre and Network Day.

This annual event in the MND Association's calendar offers an opportunity for professionals from across England, Wales and Northern Ireland to connect, share best practice and progress service development for people with MND.

Claire Lang, MND Specialist Nurse and Care Centre Co-ordinator explains. "The day allowed us the chance to step away from our clinical work and gave us brain space. It was also great for networking and there has been lots and lots to think about to take back to our teams."

This year's theme, *Best care in a shifting care landscape*, reflected the changes within MND care. Attendees were encouraged to consider how services can continue to adapt and respond to emerging challenges and opportunities.

Professor Martin Turner, Consultant Neurologist at Oxford University

Our Chief Executive, Tanya Curry, opened the event and Sally Hughes, Director of Services and Partnerships, talked about the importance of empowering people with MND to have greater choice and control.

> **“For me, it was really important for networking and to be part of the bigger picture, sharing best practice.”**
>
> Becky Thomas, Adult Speech and Language Therapist at the Nottingham Care Centre

Find out more on our website. Just scan the QR code or visit wwwmndassociation.org/education

Attendees networking and learning from each other

During the day, experts delivered presentations on topics including cognitive and behavioural symptoms, withdrawing respiratory support and communication strategies. One of the issues discussed was the Terminally Ill Adults (End of Life) Bill and its potential impact on care provision for people living with MND. For Alex Hedley, Respiratory Physiotherapist at the Nottingham MND Care Centre it sparked thoughtful discussion. Alex said: “It addressed the elephant in the room. It’s important to discuss and the event was an important forum for that discussion.”

Dr Rachel Dodds, Clinical Psychologist at Leeds Teaching Hospitals NHS Trust, added: “It was really informative. Hearing about the Assisted Dying Bill was so important and thought-provoking.”

Another key session focused on tracheostomy ventilation – a procedure that involves inserting a tube into the windpipe to help breathing. Attendees considered recent research on this practice, including clinical experiences and the perspectives of people with MND and their carers.

The final session shared work by MND care co-ordinators to improve MND care, describing the collaborative projects with centres and networks planned for the year ahead, including a new initiative exploring blended diets to support nutrition.

For many attendees, the chance to share knowledge and connect with their colleagues was invaluable. Becky Thomas, Adult Speech and Language Therapist at the Nottingham Care Centre said: “For me, it was really important for networking and to be part of the bigger picture, sharing best practice.”

Throughout the year, the MND Association organises a range of events that bring together health and social care professionals, including online webinars, study days, in-person workshops and networking opportunities. The programme is designed to support professional development and improve care for people affected by MND.

DR MICHAEL HOPE: OBITUARY

Trustee, Dr Michael Hope

MND Association trustee Dr Michael Hope sadly died in June, two years after his diagnosis of MND, at the age of 63.

Like many others in the MND community, Michael's journey to diagnosis was long and frustrating. This experience, and after seeing his uncle die from the disease, motivated Michael to become a trustee for the Association. He was elected to the Board last June.

As a trustee, Michael was a highly respected and valued member of the team. His personal experience of MND and his career in the NHS meant his contributions were significant, as he used his knowledge and understanding to maximise our impact and make improvements for others living with MND. Michael was generous with his time, becoming an integral part of our Care Services and Research Committee.

As Michael explained when he became a trustee: "I understand the difficulties for people living with MND and their carers. I've seen courage, bravery and perseverance which inspires me to stand to be of service to represent and speak for people affected by MND."

Michael was also a regular attendee and a well-liked member of the South and West Somerset Branch.

CHAIR'S MESSAGE

By the time you read this, we will have hosted our Annual General Meeting (AGM) at which we will have welcomed a new trustee to the Board and presented our 2024 *Annual Report* – you can read this on our website. Reading through it is an important reminder of just how much work is going on at the Association to support our community now, while also bringing hope for the future.

Of course, as much as we are doing, we must do more to drive us towards our vision of a world free from MND. We're now forging ahead with plans, guided by our new strategy, which include innovative projects and approaches.

In June, I was delighted to attend the launch of the Longitude Prize on ALS/MND. The Association is the principal funder of this new approach to investigating how we use artificial intelligence to speed up research. It's an incredibly interesting area, with this prize introducing new people who offer a wealth of different experience and ideas to the field of MND research. I'm very much looking forward to seeing the Prize's progress.

Similarly, I'm keen to meet our new MND Association Research Nurses – the first one has started in their role and we expect to welcome more in the coming months. Another innovative and forward-thinking idea which I'm confident will make the difference we all want to see to the future of MND support.

In finishing, I'd like to pay tribute to my fellow Board member Dr Michael Hope, who sadly died in June. Michael brought his own experience of living with MND to the role and we are so grateful for his contribution, especially as part of our Care Services and Research Committee. Michael will be missed.

CONTINUING HEALTHCARE FUNDING: PILOT LAUNCHED

People living with MND can now access specialist advice about applying for continuing healthcare (CHC) funding, thanks to a new pilot launched by the MND Association.

The project aims to help people navigate the complex CHC system. Callers to our MND Connect Helpline with queries about CHC funding, will be offered a direct referral to Beacon, an independent specialist service.

Beacon experts will then provide 90 minutes of free, personalised advocacy support. This could include advice, support with applications or following up with CHC funders about individual cases.

Applying for CHC funding can be complicated, confusing and intimidating. To qualify for CHC, the person must be assessed as having a 'primary health need'. This usually means they have nursing or healthcare requirements which cannot be met by adult social care services.

Examples of this can include:

- Complex needs which require a high level of skill to manage
- A need for ongoing care
- A condition which is changing quickly and causing concerns in managing care

The pilot, which is set to run for an initial six-month period and began on 1 April, will be evaluated regularly. The MND Association is the only charity that partners with Beacon in this way, offering a direct referral and exclusive service.

Hayley Koumas, Project Manager for Service Improvement and Transformation at the Association, said: "In the current climate, many people with MND may be wrongly paying for their healthcare and facing a worrying financial future. We were hearing that access to expert advice and advocacy was a key problem and one we wanted to address.

Hayley Koumas, Project Manager for Service Improvement and Transformation

"The pilot was developed as direct result of the coproduction work we have done, and it will support people to help navigate the complex CHC process. If a person qualifies, it can make a big difference to their care and quality of life. CHC is something we want everyone in our community who meets the criteria to have access to."

Beacon
leading you through the maze
of continuing healthcare

To access this service, and for support and information contact the MND Connect Helpline 0808 802 6262, email mndconnect@mndassociation.org or just scan the QR code to access our website

NHS Continuing Healthcare (NHS CHC)

NHS Continuing Healthcare (NHS CHC) is a package of care for adults aged 18 or over and is arranged and funded solely by the NHS.

To receive it, individuals must be assessed by integrated care boards (ICBs) according to a legally prescribed decision-making process to determine whether the individual has a 'primary health need'.

In Wales, the assessment is carried out by local health boards (LHB). There are seven LHBs that plan, secure, and deliver healthcare services within their respective geographical areas.

Beacon was established in May 2014 and provides free advice on the CHC funding to over a thousand people every month.

Additionally, you can find further information on the services available to people with MND, their families and carers on the MND Association website.

We have a specific CHC webpage which includes a video explainer, easy to digest resources, and a peer support group that meets every six weeks on Zoom.

FINDING COMFORT IN STORIES

On sleepless nights, Anita could always count on her husband Craig's voice to relax her. His storytelling had a way of calming her restless thoughts. "To be honest he could read a shopping list and it would make me happy," Anita shares.

Sadly, when Anita needed those stories most, Craig was not there to tell them. In April 2022, Craig died from MND aged just 60. Craig was diagnosed in March 2020 – a week before the first Covid lockdown. Anita said: "We were robbed of our future together. With everything shut, we couldn't even make memories in the precious time we had left."

As the disease progressed rapidly, Anita left her job as a secondary school chemistry teacher to become Craig's full-time carer. Anita said: "What he could do one week, he suddenly couldn't do the next. Within months, Craig had lost the use of his arms and hands. Within a year I was doing everything for him.

"Craig's biggest fear was losing his voice. He always said if I couldn't understand him anymore, he'd want to go. Thankfully I was able to understand him until the very end."

Anita and her husband Craig, who died from MND in April 2022

When Craig died, grief left Anita sleepless once more. The night after his funeral she visited the oldest chestnut tree in England with her brother and sister-in-law. It's sprawling roots sparked her imagination. That night, she pictured tiny characters living beneath the tree, and started telling herself stories.

What began as an act of self-soothing soon became an important way to deal with her grief. Anita said: "When I'm upset writing helps take me away from reality for a while. For me, writing is a form of therapy. Encouraged by my family, I turned my stories into a children's book which has been published to raise funds for the MND Association.

"I know Craig would be so proud. I just wish he was here to see it. He wanted to help people living with MND, but his options were limited because of Covid. He'd be pleased that he has inspired a book that will bring joy to children as well as raise money to help others affected by MND."

To order Anita's book just scan the QR code below or visit www.pegasuspublishers.com/books/anita-newton/the-under-tree-folk

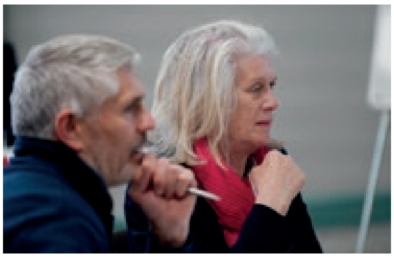
LISTENING TO OUR LOCAL LEADERS

The MND Association held its first Leadership Forum for branch and group leaders in April.

The event gave local leaders the chance to meet members of the Association's Executive Leadership Team, learn more about our strategy and share ideas for working effectively as one team.

Following positive feedback, more of these events will be scheduled throughout the year to ensure we keep the door open for greater collaboration and the sharing of knowledge.

Matthew Cobble, Head of Volunteering said: "It was fantastic to see so many volunteers attend our first Leadership Forum. Involving volunteers in shaping key parts of our work and culture is vitally important and it was great to have the opportunity to do this. I'm really looking forward to future events and the chance to do even more of this kind of partnership working in the future."



Thank you to everyone who joined us and contributed to such a successful day.

IT'S NOT JUST ABOUT THE MOTOR NEURONES

The MND Association is funding an exciting research project that aims to provide new insights into how brain cells other than motor neurones are involved in MND.

While there has been much research into how MND affects motor neurones themselves, there has been less investigation into whether other brain cells are involved in the onset and progression of the disease. Some previous research has suggested that cells which usually support motor neurones, known as astrocytes and microglia, might contribute to the damage and death of motor neurones in MND.

Dr Ben Clarke from University College London is looking into how astrocytes and microglia may affect disease progression and whether the two cell types work together to cause damage to nearby motor neurones. He will use stem cells from people with MND and healthy controls to grow different cell types in the laboratory and model what happens in MND and healthy cells. He will use these models to investigate whether there are differences in the behaviour of these cells in MND compared to the healthy cells.

If Dr Clarke can understand more about the role of these cells in MND, it could shed more light on exactly how motor neurones are damaged and lead to the discovery of new drugs that could correct the changes.

This project will run until October 2026.

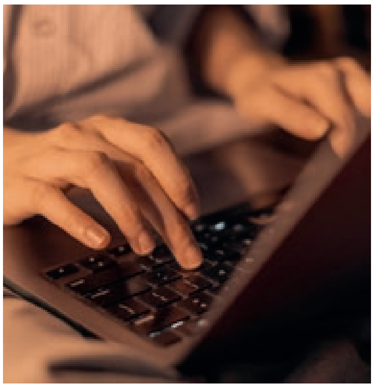
Dr Ben Clarke - University College London

Promise 3 - We won't rest until every day counts

GET INVOLVED IN MND RESEARCH

There are many ways you can get involved in MND research from filling out a survey to testing a new treatment, or by taking part in a study.

Researchers from the University of Nottingham are currently looking for homecare workers (paid carers who provide support at home) to share their experiences of caring for people with MND with complex care needs. The researchers will interview homecare workers or ask them to keep a diary of their experiences, to investigate the tasks they perform, the emotional and social support they provide, and how they work with family carers and other professionals. They hope the findings of this study will help the Association to understand more about complex care at home and improve training and support for homecare workers, which could lead to higher quality care for people with MND.



Find out more about this study and how to take part, just scan the QR code or visit: www.mndassociation.org/take-part-in-research

MATT'S MILES FOR MND

By Chris Lamb

Above: Matt Lamb and his family and right, fundraising activities

Chris Lamb was diagnosed with MND in September 2021. Since his diagnosis, Chris' family have channelled their energy into raising awareness and funds for the MND Association.

Over the past three years, his son Matt has taken on a series of tough challenges, inspiring a wave of support that has helped raise an incredible £30,000. Here, in his own words, Chris shares how proud he is of Matt and how deeply moved he has been by the kindness of everyone who supported Matt's fundraising.

When I was diagnosed with MND, my son Matt wanted to help. He set up a JustGiving page detailing two major challenges. The first was walking the Yorkshire Three Peaks with a couple of good friends. It exhausted him as Matt is built for scrummaging and not hill walking.

Undeterred, Matt then walked the 200 mile Coast-to-Coast route, from St Bees in Cumbria to Robin Hood's Bay in Yorkshire. He completed it in 19 days, joined along the way by family and friends from across Britain and Ireland.

Chris Lamb with his wife Julie

Battered by severe storms across the Lake District and baked by a freak heatwave on the North Yorkshire Moors, Matt made it to Robin Hood's Bay, so tired he vowed he'd never hike again!

Donations flooded in from family, friends, golf pals and former work colleagues from around the world. Matt's determination inspired thousands of pounds in support.

Many of my golf pals donated, some of whom had known Matt since he was a child. A group of them, called Friends of Cis United, decided to raise funds for the fight against MND. Over the past couple of years, they've contributed thousands. Thank you Friends of Cis United.

I'd also like to thank my golfing community at Richmond Golf Club, where I served as Chairman and Seniors Captain. The members have shown incredible generosity. The Seniors supported Matt's efforts by organising competitions and dinner auctions, raising thousands of pounds over the past two years. Thank you Richmond Golf Club.

Matt's attention then turned to football. His two sons play for Strensall Tigers FC, who played a charity match against their local rivals. Supporters on the sidelines donated hundreds of pounds that day. Well done and thanks Tigers.

So much support was inspired by one man's effort. But, of course, it was never just one person. Matt could never have achieved what he has without the love and support of Helen, his wife. She even took on the Squat Challenge, completing 5,000 squats. Ouch!

The total they've raised so far…£30,000. And Helen isn't done yet. She's planning more fundraising, so watch out, you've been warned.

Chris sadly died from MND in June. We publish his article with the kind permission of his family.

RESEARCH PROJECT SPOTLIGHT

MND is complex so the research we fund needs to cover a broad spectrum, from searching for causes, to developing treatments and exploring new ways of easing symptoms.

Here's a snapshot of some of the most promising MND Association funded research underway right now.

Dr James Alix

Nerve conduction tests: a helping hand for the diagnosis and prognosis of MND?

Dr James Alix and his team at the University of Sheffield are investigating whether nerve conduction tests in hand muscles could be useful in diagnosis and predicting progression. Currently diagnosing MND involves a series of tests to rule out other conditions which have similar symptoms.

Some of the tests used to help diagnose MND are nerve conduction tests which use electrical pulses to measure muscle movement. Research has suggested that these tests, when used on hand muscles, may identify MND and help predict disease progression.

If successful, hand muscle nerve conduction tools could be used as a screening test in clinics where positive results would lead to further tests to confirm MND, helping diagnose the disease faster. Earlier diagnosis means people can receive appropriate care and access clinical trials sooner. They could also help provide a more accurate prediction of disease progression, allowing people to plan for future care.

Dr Marc-David Ruepp

Developing new FUS-linked MND models to understand how this protein becomes toxic in MND

MND is known to be associated with changes in a gene called Fused in Sarcoma (FUS). These changes cause the FUS protein to move within the cell and become toxic. Dr Marc-David Ruepp, King's College London, is leading a three-year project to develop new MND models to explore how FUS interacts with other proteins in its incorrect location in the cell. The aim is to understand how FUS causes damage. By understanding the underlying biology of toxic FUS, researchers can focus on discovering new ways to counteract or reverse its toxicity.

Dr Carlo Rinaldi

Developing a new potential treatment for Kennedy's disease

Kennedy's disease is an inherited form of MND which is caused by a mutation in the gene which holds the instructions to make a protein called the androgen receptor (AR). Blocking AR activity is thought to be a potential treatment strategy.

Dr Carlo Rinaldi, at the University of Oxford is developing a protein called AR45, which acts as a switch for the AR. This project will increase understanding of how changes in the gene for the AR contribute to the development of Kennedy's disease. It will also investigate how AR45 works within the body and may lead to further lab-testing to determine whether it may be a promising treatment.

For more information about the research we fund, visit www.mndassociation.org/research-we-fund

WHO’D HAVE THOUGHT?

By Mike Willis

Mike Willis, who is living with MND, explores if he can communicate with brain waves.

Filming for BBC's The One Show at Nottingham Trent University with Mike Willis, Lindsey Burrow, Sharmila Majumdar and far right, Professor Amin Al-Habaibeh

‘I’d do anything to get my speech back’, I remember typing on the keyboard last year, and then hearing my AI (artificial intelligence) voice clone speak the words to my friends, sounding exactly like I used to.

I’d heard of attempts to restore speech using chips connected to the brain, but when I looked into it, it requires brain surgery! Even if it became available on the NHS, that isn’t going to work for someone like me who feels faint at the thought of a blood test.

Then I heard about Professor Amin Al-Habaibeh and PhD researcher Sharmila Majumdar’s development of a prototype low-cost brain computer interface (BCI) that they’d developed at Nottingham Trent University. No surgery required, not even shaving off clumps of hair to attach carefully positioned EEG electrodes to my scalp.

“Imagine there’s an elephant in the room,” said Amin. I’m sitting quietly, with my eyes closed. I concentrate and imagine staring face-to-face with an elephant. Amin said: “Now imagine you’re dancing to your favourite song.”

You see, the way the system works is to record your brain waves, detected by the electrodes, while you are thinking of something. Research had determined that these two ‘imaginations’ – the elephant and dancing – would generate different patterns of brainwaves that could be reliably detected.

In the training session I had to repeat the ‘elephant’ and ‘dancing’ imaginations 20-30 times. Then, back at the University lab, Sharmila had used AI to analyse the wiggly patterns of waves I’d generated.

At the test session the electrodes were stuck to my scalp. I sat trying hard to relax. That was tricky in a room filled with a camera crew filming me for BBC’s *The One Show*, Lindsey Burrow, who was interviewing me, people from the MND Association, Loraine my wife, and Amin and Sharmila.

Amin said: “Think of one of the imaginations.” After a few seconds Sharmila’s mouse clicks on the laptop, Amin looks at the result on the screen and said “elephant”, “yes” I replied. Everyone in the room gasps, it works!

We repeat the test a few times and the system reliably predicts ‘elephant’ when I think of it. So, how could such a system be of any use, unless I’d like an elephant or to go dancing? Well, the concept is that one ‘imagination’ could indicate ‘yes’ and the other ‘no’. Would I like a cup of tea? ‘Dancing’ meaning ‘No’.

Neurotechnology is coming along fast, connecting the brain or nerves to computers. BCI’s don’t just mean brain implants. Simpler, affordable systems may be possible, as this development has so clearly shown.

So, do I think this BCI should be developed? Would I use such a system? Would it be useful for those with MND? Elephant, elephant and elephant!

“I’d heard of attempts to restore speech using chips connected to the brain, but when I looked into it, it requires brain surgery!”

Mike Willis

TIM-R: A REMOTE PLATFORM FOR MND RESEARCH

Do you want to take part in MND research but not sure where to begin?

TiM-R is a new digital platform that will make it easier for people across the UK to take part in research. It aims to bring all of the UK MND research studies into one place so people can see what research is happening and find out more.

Scan the QR code to find out more about TiM-R and to sign up

LEAVE A LASTING LEGACY OF SUPPORT

Gifts left in Wills have the power to change the world – that's the message being shared as part of Remember a Charity Week in September.

While writing a Will is key to making sure your family and friends are looked after in the years to come, it also offers a powerful way to remember the charities which matter most to you, creating a lasting legacy of support. The week-long event from 8-15 September will encourage everyone to think about how they would like to be remembered and to consider leaving a gift to charity at the same time.

Last year, Gifts in Wills accounted for around 25% of the MND Association's income, allowing for greater investment in support for people living with MND, their families and carers as well as the future of MND research.

In May, a group of MND Association supporters were able to learn more about the progress being made in MND research at a Meet the Researchers event held at the University of Nottingham.

During the event Professor Rob Layfield, Dr Dan Scott and the MND Association's Programmes and Partnerships Manager, Sophie Nyberg spoke about the difference gifts left to the MND Association can make to the future of MND research, while Ann Gretton and Liam Blaney spoke movingly about their own personal experience of MND.

To learn more about Gifts in Wills and the difference they can make simply scan the QR code or visit www.mndassociation.org/legacies

THANK YOU

TO ALL OUR FUNDRAISERS

BOOST FOR LOCAL GROUP

£3,000

The Furness and District Support and Fundraising Group received a £3,000 donation from Unite Union. Group and union member Peter Wall recommended Unite donate to the group, to help people affected by MND in the local community. Peter's wife died of MND in 2022.

SPINATHON SUCCESS

£3,000

Jade Blakeley powered through a four hour spinathon, raising over £3,000 in memory of her dad Stephen, who died from MND. She said: "The spinathon was more than just a fitness challenge - it was a tribute."

THANK YOU, JULIE

£2,000

The South Lancashire Branch would like to thank Julie, who ran the London Marathon in memory of her mum Brenda, who died from MND when Julie was just 18. Julie's cousin Neil and auntie Ann also died from MND, so the cause is deeply personal to her.

CAPTAIN'S CHOICE

£15,000

Edward Brown chose to support the MND Association as his Captain's Charity during his term at Huddersfield Golf Club. With a charity summer ball, golf day, collection tins and donations, the club has raised the grand total of £15,000.

PEDALS AND PEAKS FOR PAUL

£14,500

Paul Whitehead set himself an endurance challenge to cycle from Land's End to John O'Groats and climb the Three Peaks along the way. Paul was inspired by his friend Steve, who is living with MND. He described his journey as 'nothing compared to the physical challenges Steve faces every day'.

BUILDING SUPPORT

£10,000

A huge thank you to the Exeter Construction Group fundraising committee for hosting a glamorous winter ball at the University of Exeter in February. The evening raised an incredible £10,000.

100 MILES FOR ADAM

£2,500

At 81, Jenny Gibbs walked 100 miles in January after her son-in-law Adam was diagnosed with MND. Inspired by our 'Run 31 Miles' challenge, she tweaked it to 'Walk 100 miles in January', raising over £2,500. Braving all weather, her determination moved Adam, who said: "We're blown away by her love and grit. She's one in a million."

OUR OLLY

£3,550

Jason, Gary, and Kate completed the Great Birmingham Run, raising £3,550 for the Hereford and Worcestershire MND Branch to honour their friend Olly who is living with MND. Jason said the support Olly receives from the Branch is essential for him and others coming to terms with the disease and taking part was their way to raise awareness and funds for MND research and care.

DARTS MARATHON

£2,280

Charlotte Parsons and her partner held a 24-hour darts marathon in memory of their friend Mick, raising £2,280. Charlotte said planning the event over 11 months—from posters to raffle prizes—was a joy. "It was a blessing to see so many people come together to create something amazing for such a meaningful cause."

KICK OFF IN KINDNESS

£5,454

Astley FC held a charity football match in May, raising an incredible £5,454 for their friend Lucas Hall, diagnosed with MND in 2024. With support from Jade of the Central and East Lancashire Branch, the day was a huge success - and they're not stopping there, with more fundraising planned this summer.

REMEMBERING GILLIAN

£21,070

Trentham Golf Club Captains Fiona Ford and Mark Phillips raised an outstanding £21,070 during their year in office in memory of Gillian Gee, a much-loved member, and 2019 Lady Captain. Gillian was diagnosed with bulbar onset MND in 2023 and attended several fundraising events before her death in September 2024. A remarkable tribute to her legacy.

ULTRA-DETERMIND

£4,836

In June, Team STQ completed their second ultra challenge in memory of Jennifer Emerton. Her sons, Sam and Ben, joined by family, friends, and STQ Partners all took part in the Lake District Challenge. They've raised an impressive £4,836 so far, with donations still coming in. A heartfelt thank you and well done.

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**

GREEN PAPER WORK CONSULTATION - OUR RESPONSE

The MND Association has submitted a response to the Government's Pathways to Work Green Paper consultation which sets out reforms to health and disability benefits and employment support.

The consultation proposes:

- Replacing Work Capability Assessments with decisions based on Personal Independence Payment (PIP) criteria for Universal Credit (UC).
- Raising the qualifying threshold for PIP's daily-living component.
- Freezing or cutting the UC health element for new claimants.
- Delaying access to health-related UC elements until people reach 22.
- Imposing more challenging work-related requirements on those receiving health-related benefits.

These measures would undermine the financial security and dignity of people with MND who, once their condition has forced them to stop working, are highly unlikely to return. We've urged the Government to:

1. Grant automatic, non-means-tested access to the highest rates of PIP and the UC health element from the point of an MND diagnosis.
2. Provide a blanket exemption from all work-related requirements for anyone with MND.
3. End repeat reassessments once a diagnosis is confirmed.
4. Protect existing benefit levels so no one with MND is left worse off.

We're campaigning in partnership with the Disability Benefits Consortium to secure quick and fair access to financial support for everyone with a progressive or terminal illness, safeguards to prevent erosion of current entitlements and the ongoing involvement of disabled people and relevant charities in shaping future reforms.

What happens next?

A Government White Paper is expected later this year, followed by draft legislation and further consultation. We will continually review and submit evidence, and consider opportunities to influence MPs and peers.

For free support contact our benefits advice service: www.mndassociation.org/support-and-information/our-services/benefits-advice

INFORMATION UPDATES

NEW RESOURCES

Our new *Psychological and social care support* infographic is designed to help professionals discuss impact and provide support during MDT assessments and other appointments.

Revisions

We have updated the following resources:

- *10C – Disabled facilities grants and home accessibility*
- *Publications order form*
- *An introduction to motor neurone disease (MND) audio version*

If you are going on holiday…

MND Alert card

Our newly revised MND Alert card comes with downloadable cards in other languages to use abroad, available on our website. If you need the card in more languages, contact MND Connect.

Getting around

Our *Getting around with MND or Kennedy's disease* booklet has guidance on getting out and about with reduced mobility.

Information you can trust

We're pleased to announce that, following assessment, we have maintained our national accreditation for the production of trustworthy health information, with the PIF Tick: **www.pifonline.org.uk/pif-tick/**

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 care information finder at: **www.mndassociation.org/careinfofinder**

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**

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.

LATEST EPISODES

Episode 36: Driving change for the MND community

Chief Executive Tanya Curry and Director of Engagement Richard Evans reflect on a landmark year for the Association - highlighting record fundraising, expanded grants, bold advocacy, and our research nurse network. They share how the charity is focused on delivering more impact through faster access to emerging treatments, targeted support, and a louder voice for the MND community.

Episode 35: Transforming MND research with AI: Longitude Prize on ALS

Helen is joined by Tris Dyson from Challenge Works, and the MND Association's Dr Mike Rogers and Dr Brian Dickie, to explore the groundbreaking £7.5 million Longitude Prize on ALS. This global challenge aims to revolutionise drug discovery by harnessing the power of artificial intelligence. Tris, Mike and Brian discuss the exciting prize, which is open for entries until December.

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**

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MND CONNECT

Our **MNDConnect helpline** offers advice, practical and emotional support and signposting to other organisations. **Open Monday to Friday 9am to 4pm**

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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