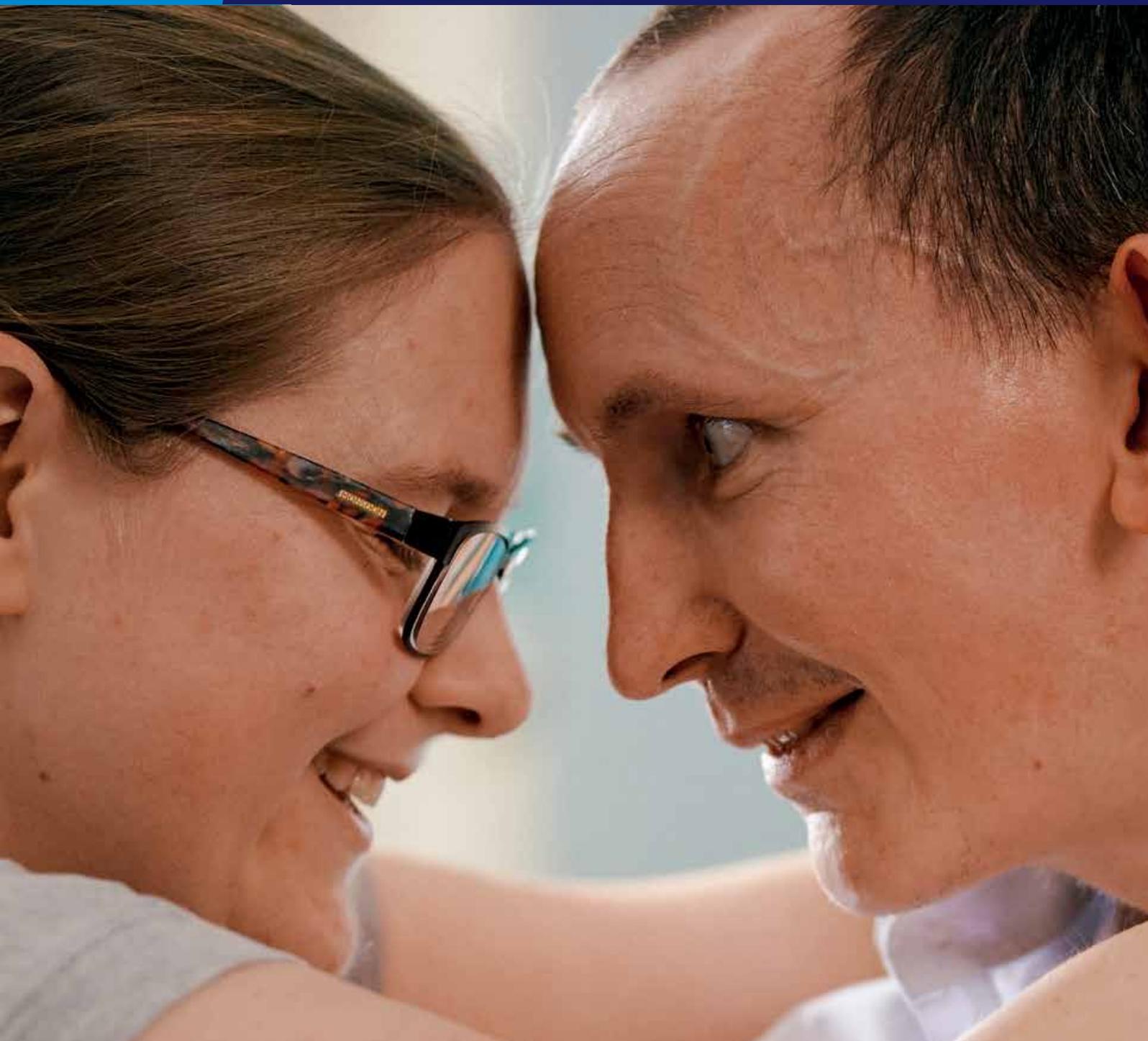




# THUMBPRINT

NEWS FROM THE MND ASSOCIATION COMMUNITY

SPRING 2024



## A new level of awareness

Coronation Street viewers show their support for the MND community

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Available in men's, women's and youth sizes

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Or scan the QR code



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Celebrating the work of three Association-funded researchers

On the cover: Mike Sumner and his wife Zoe who feature in our awareness campaign



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# Welcome

## from our Chief Executive

It was an honour to welcome our Royal Patron, HRH The Princess Royal to a wonderful afternoon tea at Leeds Rhinos' AMT Headingley Stadium in February. The Princess joined us as we thanked 80 specially invited guests for their tireless efforts raising awareness and money, inspired by our patron Rob Burrow. Her Royal Highness was so generous with her time, chatting to individuals and sharing her own thoughts about their endeavours in a personal speech.

In April, we headed to Northern Ireland for our inaugural Regional Roadshow. This was my first time meeting the Northern

Ireland Branch and I was joined by a couple of new members of our Executive Leadership Team. We've launched the Roadshows to give us the opportunity to have face-to-face conversations with people affected by MND, members of our branches and groups, volunteers and supporters. As we work hard to shape the future of the Association, building a solid strategy to deliver the five Promises we have made to our community, your support is vital. We want to share our thoughts but, more importantly, we want to listen to and learn from you – if you'd like to get involved in the conversation, please sign up to join us at a future Roadshow on our website [www.mndassociation.org/events/regional-roadshows](http://www.mndassociation.org/events/regional-roadshows).

You may have seen the extremely disappointing news that the National Institute for Health and Clinical Excellence (NICE) has decided tofersen should be evaluated as a potential treatment using, what we believe, is the wrong process. The decision goes against advice from world-leading MND researchers and clinicians, and will almost certainly mean tofersen won't be available for people who desperately need it. As a reminder, tofersen has been proven to slow the progression of MND in people with the genetic SOD1 form of the disease – that's around 2% of those with MND or around 100 people in the UK. We're taking steps to urge NICE to reconsider this decision and will keep you updated on our website and social media channels.

The decision is also a timely reminder of why research is so important – to give us the best chance of a proven, effective treatment becoming available we have to keep topping up the research pipeline. We are currently funding 220 researchers. And of course we are entirely reliant on you, our passionate and committed supporters to do that. Thank you so much for everything you continue to do.

I look forward to meeting more of you soon!

Tanya Curry, *Chief Executive*



# £5 million investment to give more people with MND access to clinical trials

**The MND Association is investing up to £5 million over the next five years in a new initiative, the MND Association Research Nurse Network across England, Wales and Northern Ireland. The Network aims to give everyone diagnosed with the disease an opportunity to take part in vital research. The first nurses are expected to be in post by the end of the year.**

Currently, access to trials depends on a number of factors. This can include a person's proactivity in seeking opportunities, the knowledge their health and social care team has of research trials and where they live, as many clinical trials only take place in a small number of locations. The Network will bring equitable access, with the opportunity to take part in clinical research and trials as part of each person's holistic care.

The initiative will bridge the gaps between researchers, care teams and people with MND. It will take research and trials directly to people with MND through their local Care Centres and Networks, ensuring access to research is an integral part of their care.

Specifically, MND Association Research Nurses will help people with MND navigate the research trial process – providing information, identifying trials and research opportunities patients are eligible for, explaining what's involved, and supporting their ongoing involvement. They will support the needs of each person to make what is a really personal choice, and then guide them through the process. Importantly, collaboration across the Network will support the sharing of outcomes, so successful research can be put into practice quickly.

Dr Brian Dickie MBE, Director of Research Development at the MND Association said: "Historically, there have been limited opportunities for people with MND to access clinical trials. The recent explosion of new scientific understanding of MND is creating exciting new treatment strategies which, in turn, are starting to generate opportunities for more trials. We want to create an environment where everyone diagnosed with the disease has options.

"By establishing the MND Association



**We know that patients want the opportunity to participate in research and that health professionals at MND Care Centres want to be able to offer this to their patients.**

Professor Christopher McDermott,  
Co-Director of the UK MND  
Research Institute

Research Nurse Network we believe more people will be recruited into trials more quickly and that can only help speed up the pace of research towards potential treatments and ultimately a cure for MND."

MND Association Research Nurses will work alongside established multidisciplinary teams in Care Centres and Networks where the MND Association currently funds the co-ordination of care and support for people with MND.

Professor of Translational Neurology Christopher McDermott, Co-Director of the UK MND Research Institute said: "We know that patients want the opportunity to participate in research and that health



**This is really fantastic news for our patients and for the MND Community as a whole. It is fantastic that the MND Association recognises the worth of research and care working hand in hand for people with MND.**

Beth Pudjianto, Care Centre  
Co-ordinator at the Birmingham  
Care Centre

professionals at MND Care Centres want to be able to offer this to their patients. But I've noticed a steady decline in MND centres' ability to participate in MND research in recent years as a result of the increasing complexities of trials, the pressures within the NHS and the prioritisation of research support for other areas. This investment by the MND Association will mean MND Care Centres and Networks will have dedicated staff to offer new research opportunities to their patients."



PROMISE 2  
WE WON'T REST UNTIL  
**EVERYONE GETS THE CARE  
THEY NEED WHEN THEY NEED IT**



**By establishing the MND Association Research Nurse Network we believe more people will be recruited into trials more quickly and that can only help speed up the pace of research towards potential treatments and ultimately a cure for MND.**

Dr Brian Dickie MBE, Director  
of Research Development  
at the MND Association

# The Love Inside

## connecting communities



Louise and Rob

**'Heart-breaking'. 'Heart-wrenching'. 'Beautiful'. 'Real'. The MND community came out in force to give its verdict on our first TV advert for more than a decade, broadcast during Coronation Street commercial breaks.**



Mike and Zoe

The advert was watched by more than six million people and is one of a series featuring Louise Jordan with her husband Rob, Mike Sumner with his wife Zoe and Mike Small with Association Area Support Co-ordinator Alli Anthony.

The adverts show the devastating impact of the disease, while also focussing on the powerful connection between the pairs. Called *The Love Inside*, the adverts are set to Roberta Flack's song *The First Time Ever I Saw Your Face*, and end with the on-screen message 'Motor neurone disease takes everything, but it can't take the love inside'.

Within minutes of the first broadcast, messages were flooding in on social media from people affected by MND and *Coronation Street* viewers whose main knowledge of the disease comes from seeing character Paul Foreman living with it on 'the cobbles'.

For Sarah Ezekiel, who is living with MND, the advert brought back memories of being involved in the Association's cinema advert in 2010. Sarah said: "When

I appeared in *Sarah's Story*, there was very little awareness of MND. Unfortunately, it was banned from TV for being too shocking, which was disappointing.



**I'm pleased to see *The Love Inside* advert on TV now and I think it's touching and heartfelt. Instead of being the hidden disease which it was before, MND is now increasingly visible which will help to find a cure and put an end to this awful disease forever.**

"I'm pleased to see *The Love Inside* advert on TV now and I think it's touching and heartfelt. Instead of being the hidden disease which it was before, MND is now increasingly visible which will help to



**PROMISE 4**  
WE WON'T REST UNTIL  
**YOU ARE HEARD**



The response to the campaign has been incredible. But the devastating impact of MND hit hard when Louise Jordan and Mike Small sadly died before seeing the adverts featuring them broadcast.

Chris James, Director of Engagement, MND Association



out more about MND and support our work. Media coverage included actor Dan Brocklebank's interview on ITV's *Good Morning Britain*, and Mike and Zoe's appearance on ITV's *This Morning* and in *The Mirror*.

Chris James, Director of Engagement at the MND Association, said: "The response to the campaign has been incredible. But the devastating impact of MND hit hard when Louise Jordan and Mike Small sadly died before seeing the adverts featuring them broadcast.

"This is a stark reminder of the urgency we must have. MND is rapid, and we need to be too. That was a big part of the rationale for investing in this campaign to reach millions of people who may not have been aware of the MND Association.

"Reaching and engaging with these new people is vital for us to continue our

work. We've seen a huge outpouring of love from the ITV audience to the MND community, and are now working to turn that love into action to bring new volunteers, fundraisers and supporters onboard."

The adverts will be broadcast on ITV until the autumn.



find a cure and put an end to this awful disease forever."

Alongside the TV advert launch, the campaign included digital billboard displays in London, Birmingham and Manchester, ongoing social media content and a new area of the Association's website encouraging those inspired by the adverts to find

## What you thought of the tv adverts





**RESEARCH SPOTLIGHT**  
THE LATEST PROMISING  
RESEARCH PROJECTS

## The Francis Crick Institute to open its doors to MND Association supporters

**Building relationships with key research institutes across the UK is vital to progress MND research. We are currently funding 109 research projects across 19 UK universities and research institutes.**

The MND Association has a long-standing relationship with University College London (UCL) and its researchers. This relationship has helped forge new connections, including with The Francis Crick Institute in London, a flagship centre for discovery research in biomedicine. These institutes work closely together to increase our understanding of what's going wrong in motor neurones and investigate new potential treatments. Currently, we are funding 14 research projects across these institutions.

In May, The Francis Crick Institute is opening its doors to supporters of the MND Association for a special event. As

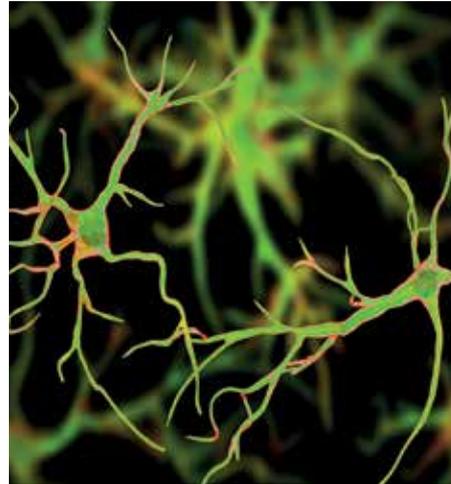
well as being a great opportunity to find out more about the latest research developments, the event will also showcase the difference that gifts in Wills make to funding key research into MND.

Here is a small taste of some of the exciting research being undertaken by researchers at University College London and The Francis Crick Institute.

**If you would like to find out more about the Legacy event, please contact the Legacy team on 01604611799 or e-mail [legacies@mndassociation.org](mailto:legacies@mndassociation.org). You can find out more about the research we fund on our website: [www.mndassociation.org/research/our-research/research-we-fund](http://www.mndassociation.org/research/our-research/research-we-fund)**

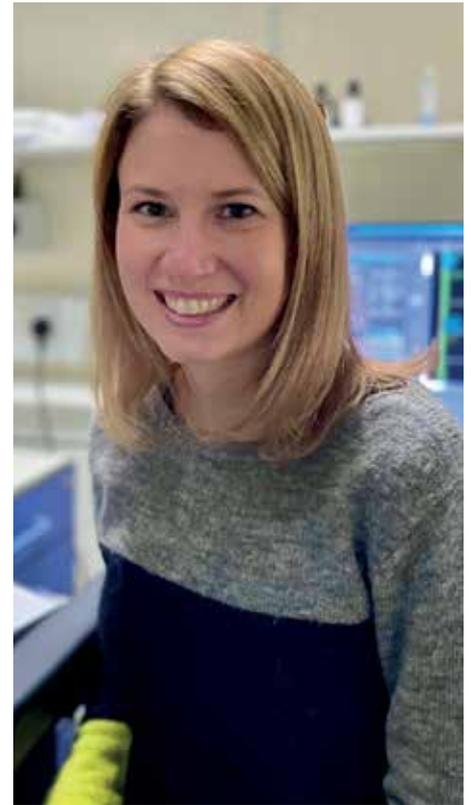


**PROMISE 1**  
**WE WON'T REST UNTIL**  
**MND IS TREATABLE AND ULTIMATELY CURABLE**



Dr Clarke is growing cells to help look for changes that happen in MND compared to people without the disease. Once any changes have been identified, Dr Clarke will try to see if the changes can be corrected. It is hoped this research will lead to new potential treatments for MND.

this could contribute to motor neurone damage. The researchers are testing different molecules to see how effective they are at correcting the mistakes in the instructions to make UNC13A. The most promising candidate could then be further developed and potentially tested in clinical trials.



*Dr Nicol Birsa*



*Dr Ben Clarke*

### **Developing a new gene therapy**

Professor Pietro Fratta, Dr Oscar Wilkins and team are developing a new cutting-edge gene therapy which could lead to a potential new treatment for MND. Research has shown that a protein called TDP-43 is faulty in 97% of people with MND. Faulty TDP-43 can cause mistakes in the instructions which make other proteins and as a result these proteins can also become faulty.

One of these proteins, called UNC13A, plays an important role in how motor neurones communicate. When UNC13A doesn't work as it should, it is thought

### **Investigating cells that surround motor neurones**

Previous research has suggested that cells which support and surround motor neurones, known as microglia and astrocytes, can contribute to motor neurone death. Dr Ben Clarke is investigating whether the cells work together to cause damage.

### **Looking at the impact of proteins**

Proteins are vital in performing all the key tasks needed to keep a cell healthy. When proteins are made differently, this can stop them from performing tasks correctly and can lead to cell death. Fused in Sarcoma (FUS) plays a key role in controlling how other proteins are made. FUS is known to be faulty in some people with MND and this disrupts the production of other proteins.

Dr Nicol Birsa is investigating how this disruption alters the function of motor neurones and how they connect to muscles. Once it is understood how motor neurones are damaged, Dr Birsa will investigate if it is possible to correct the damage. Understanding the changes to motor neurones in MND is crucial in designing new effective treatments.

# “For one of our own”

## Colleagues show their fundraising support

**When a young family was given the earth shattering news that their wife and mum had MND, friends and colleagues felt they had to do ‘something’ to show their support. That ‘something’ has turned into a staggering £90,000 donation for the MND Association.**

Fortune Hill and The Marketing Society hosted a marketing-themed quiz at LinkedIn’s London HQ. During the evening the friends and colleagues unearthed trivia gems such as Google’s original name – Backrub, cracked the enigma of the cryptic clue ‘fantastic narcotic’ – Superdrug, and reaffirmed what can be achieved when they come together as a community.



Joel Barnett, Managing Director at Fortune Hill shared why this event felt so personal to everyone attending. Joel said: “Our collective spirit raised an impressive £90,000 for the MND Association as a heartfelt gesture of support for Gary Bramall, one of our own, whose life has been affected by this cruel, incurable disease.”

Gary, the former Chief Marketing Officer at Zoopla, is now a carer for his wife Sam, the mother of their two young children. Gary said: “I’ve been incredibly fortunate in my career to be part of a community populated by phenomenally kind, mind-blowingly smart, and wonderfully creative people. I’m touched by their support since Sam’s diagnosis.

“Two years ago Sam fell ill. Since then, our world has been turned inside out. I’ve been caring for Sam full-time for over a year now, while helping explain the circle of life to our two beautiful, confused, heartbroken young children.

“We used to be a very fit, happy, healthy and active family. Now, we are only surviving, living hour by hour, day by day, just about coping as we crack and break from the struggle of the physical decline. In some ways we are the lucky ones, we have family and friends to support the

24-hour care we need. We have many shoulders to cry on, and we are financially ok for now. But so many aren’t as lucky as we are. The MND Association is amazing. But they are vastly underfunded, and under-resourced to deal with the weight of support needed to carry families and patients through this god-awful journey.”



**We have many shoulders to cry on, and we are financially ok for now. But so many aren’t as lucky as we are.**

Fortune Hill is determined to continue its fundraising and is already planning another event. Joel said: “We committed to supporting the fight against motor neurone disease as a show of support for a member of our community. The natural choice was to work with the MND Association. They provide invaluable support to people suffering; both those with MND and the people whose lives are devastated by the disease’s impact on their loved ones. We are incredibly proud of our community’s effort.”



# The fastest Philapillar in town

Fitting tribute to keep Phil's legacy alive



Rich Bidgood, Hugh Tibbs, Nick Wright, David Mills, James Bewley and Marcus Green wearing the six-person caterpillar costume, named the Philapillar

## How do you pay tribute to a man who, when living with MND, broke two Guinness World Records?

Phil Rossall has been featured in *Thumb Print* many times over the years, for his creative and incredible exploits. You may have read about his world records for fastest half marathon and fastest marathon pushing a wheelchair with his friend Marcus Green. Or, his blinkathons, blinking his way up Mount Everest and from John O'Groats to Land's End.

When Phil died last year at 70, his friends, dubbed TeamPhil, knew they had to do something big in his memory.

Phil's wife Brenda said: "Phil was very positive, often saying 'you're never too old or too ill to do something amazing'. He wanted to raise money and awareness, while at the same time making people laugh.

"When Phil died, Marcus said we must keep his legacy going. He came up with the idea of attempting the fastest half marathon and marathon in a six-person caterpillar costume, named the Philapillar. I immediately thought Phil would love it."

TeamPhil smashed their first Guinness World Record attempt on 3 March for fastest half marathon in a six-person

costume. They took 40 minutes off the previous record to finish in 1 hour 19 minutes 50 seconds.

The team, comprising Rich Bidgood, Hugh Tibbs, Nick Wright, David Mills, James Bewley and Marcus Green, are now training for the Manchester Marathon in the hope of setting a new Guinness World Record for the fastest marathon in a six-person costume.



**Running for the MND Association, we aim to do something exceptional to grab people's attention and use this platform to raise lots of money for the charity.**

Speaking about the challenge, Marcus Green said: "Despite his diagnosis, Phil retained incredible positivity, and lived his last years with purpose, breaking two Guinness World Records, writing two books and doing multiple blinking challenges in aid of the MND Association.

Since his diagnosis in 2016, he raised over £55,000 and we want to continue his legacy.

"Running for the MND Association, we aim to do something exceptional to grab people's attention and use this platform to raise lots of money for the charity. Going for these Guinness World Records in the Philapillar costume is a great way to do this. We want to offer encouragement to those who are living with or affected by the illness, but also make the public aware of how cruel this disease is, in the knowledge that their donations will help fund a cure and provide support for those with MND."

TeamPhil has been training hard for the marathon. Running at exactly the same pace as five other people without seeing where your feet are for 26.2 miles is quite the challenge.

Brenda will be there to cheer on TeamPhil at the Manchester Marathon. "It's incredibly heart-warming to see the lengths TeamPhil are going to in order to continue what Phil started. I can't think of a better way to honour him."

To show your support for the Philapillar visit <https://justgiving.com/marcus-green13>

# South West MND Care Network

## secures ongoing funding

**The MND Association has successfully secured long-term funding commitments from both NHS Devon and NHS Cornwall and the Isles of Scilly for essential care for people with MND in the south west.**

The news comes after years of work to establish a collaborative partnership between the MND Association and the NHS, for the South West Peninsula MND Care and Research Network.

The Association was the sole funder of the Network since its creation in 2009, until the NHS agreed to trial a joint funding approach in 2022. An evaluation of the service and the benefits it provides for people with MND was accepted by the NHS, and a promise of ongoing, recurrent funding has now been confirmed.

The Network currently includes four MND Care Co-ordinators and an Administrator, who provide a single point of contact for someone living with MND to ensure a joined-up approach to their care needs.



*Derriford Hospital, Plymouth where the South West Peninsula MND Care Network is based*

Chris Bennett, Head of Regional Services and Partnerships, said: "We're delighted with this agreement with the NHS. The success of these negotiations is even more important given the challenging backdrop of NHS finances. We've built an incredibly collaborative partnership

with colleagues in the NHS and we're delighted they have agreed to co-fund this vital support from now on, providing much-needed security for this service. It also ensures the Network can continue to deliver and further develop excellence in MND care in the south west."

## HRH The Prince of Wales

### surprises Rob Burrow and Kevin Sinfield with their CBEs

**HRH The Prince of Wales surprised MND Association patrons Rob Burrow and Kevin Sinfield by presenting them with their CBEs during a visit to Leeds Rhinos' AMT Headingley Stadium.**

Rob and Kevin, who were made CBEs in the New Year Honours List for services to MND awareness, were recognised by Prince William for their 'phenomenal' efforts. Watching on

proudly were Rob's wife Lindsey, his three children Macy, Maya and Jackson, and Kevin's wife, Jayne.

To Rob, Prince William said: "The most amount of thank yous and congratulations for all the inspirational work you've done Rob, you've been amazing and everyone's so proud of you. We've been following your case and all the money you've been raising, and you're changing people's lives with MND."

After receiving his CBE, Rob said: "It is an honour to accept on behalf of the whole MND community. Days like today allow us to keep the spotlight on the disease and continue to raise awareness and, hopefully, funds to fight the disease and support those who are living with MND and their families.

"It was wonderful that His Royal Highness was able to come to Headingley to see us and very much appreciated. It was lovely to talk to him and for him to meet my family."

Tanya Curry, Chief Executive of the MND Association said: "We're truly delighted that Association patrons Rob Burrow and Kevin Sinfield have been presented their thoroughly deserved CBEs by HRH The Prince of Wales. It is astounding how much Rob, Kevin and their families and friends have achieved since Rob's own diagnosis with the disease, raising awareness and vital funds. It is so poignant that such a special moment should happen in such a special place for both Rob and Kevin."



*HRH The Prince of Wales flanked by Rob and Lindsey Burrows with their children, Macy and Maya on the left, Kevin and his wife Jayne on the right*

# Craft challenge

creatives raise funds through crafting

**We've been overwhelmed by the creative talents of the 2,000 supporters who took part in our Craft in March challenge. Together they knitted, sketched, sewed, painted and crafted their way through the month and raised an incredible £85,000.**

Rachel Risborough has completed a series of fundraising challenges since her mum was diagnosed with MND in 2016. Rachel said: "When I saw the Craft in March challenge, I had the idea to portray our story with MND in my paintings. I took to painting around the time my mum was diagnosed and it was my peace amongst all the hardships we faced. MND has stripped my mother of her freedom but not her bravery, her smile, her caring nature and I wanted to show that in my paintings. I named my artwork collection Dawn – my mother's name. Meaning first



Rachel Risborough



Fran Burley

appearance of light, it's very fitting to my collection I made specifically to raise funds for the MND Association."

Fran Burley is a keen crafter and signed up to join the challenge in memory of her dad, Gordon, who had MND. She said: "My dad was always so full of fun and laughter; he was never afraid to be silly and was the best ear wiggler ever seen! His MND progressed very quickly. The MND Association, particularly our family support worker Sam, was amazing, providing support and helping us understand that we were not alone in this horrendous disease."

Gordon received support to bank his voice and had grants to help with the

financial cost of his diagnosis. Fran and her sister who also helped care for him received a carers grant which they used to have a pamper day together. Their children, who were very close to their grandad, received memory boxes to help them understand more about his diagnosis and create special memories together. Fran said: "I just wanted to help fundraise so other people could benefit, like we did, and maybe even aid in a step towards more understanding and possibly a cure."

If you would like to use your crafting skills to raise money, then visit [www.mndassociation.org/fyw](http://www.mndassociation.org/fyw) to receive a fundraising pack.

## "Veterans Support Group helps us relive our former active lives"

**Our online Veterans Support Group is open to military veterans living with MND. The group's hosts are Area Support Co-ordinator, Dawn Pond and Gil Boyd, who is living with MND. Gil explains how attending the monthly group helps its members.**

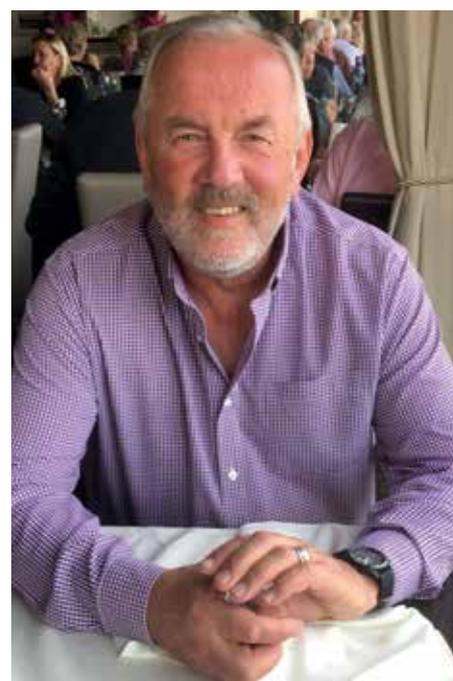
"I served in the British Army with the Parachute Regiment, served latterly in a Reserve Forces unit, retiring as a Regimental Sergeant Major.

"The group is relaxed to ensure we cover all subjects of interest for all three armed services: the Royal Navy/Royal Marines, the Army and the Royal Air Force. The sessions mainly focus on people's needs and requirements on their journey with MND to ease their path. We

also promote useful equipment in each monthly meeting, such as the recent free Apple voice banking service, which has proved a good alternative to other voice banking options.

"The group renews comradeship and I believe it combats loneliness and helps us all to relive our former active lives with people who understand what the military life was like. We can use the banter we used when we were younger and fitter!"

**Support groups can play a crucial role enabling people with or affected by MND to come together and share experiences. Visit [www.mndassociation.org/online-support-groups](http://www.mndassociation.org/online-support-groups) to find out more.**



Veterans Support Group co-host Gil Boyd

# Voting begins soon to select four new Association trustees

**In May, we will be opening trustee elections and inviting members to vote for trustees to fill four positions on our Board of Trustees.**

Trustees are a group of volunteers with legal responsibility for the Association. They act together to govern the Association and play an important role in making a difference to the lives of people affected by MND.

Trustees are responsible for ensuring the aims of the MND Association are met. That's why it's important they have the ability to think and plan strategically for the future, while focusing on the needs of all people affected by MND today. You can find out more about our Board of Trustees at [www.mndassociation.org/about-us/our-people/our-trustees](http://www.mndassociation.org/about-us/our-people/our-trustees)



## Your role as a member

Our members have a key role to play in shaping the governance of the Association. Each member is entitled to vote for elected trustees. Members will receive a ballot paper in May and will be able to vote ahead of the Annual General Meeting. Ballot papers will be sent out by our election provider Civica, so please look out for them in the coming months.

## Annual General Meeting

The Annual General Meeting (AGM) gives our members the opportunity to ask questions, hear about the work we do and play a key role in the governance of the Association by voting on matters of business, called resolutions. The AGM is also a time to welcome new trustees to the Board.

This year's AGM will be on Wednesday

26 June and will be hosted online from our central office in Northampton.

We will be joined by guest speakers from research, and services and partnerships, who will share the latest developments in these areas.

The AGM is also a chance for members to ask questions of the Board of Trustees, the Chief Executive and the Executive Leadership Team.



*Dr Usman Khan, Chair*

## Chair's message

**As spring approaches, I'm very happy to report on a particularly busy and successful first quarter. A particular highlight for me was the event the Association hosted at the Leeds Rhinos' AMT Headingley Stadium. Attended by our Royal Patron The Princess Royal, the event was both a celebration of our partnership and the remarkable achievements of Rob Burrow CBE and Kevin Sinfield CBE, and an opportunity to thank individuals for their incredible fundraising exploits.**

Looking forward, I would like to highlight our forthcoming series of Regional Roadshows. These provide an excellent opportunity for myself, fellow trustees and the Executive Leadership Team to meet with the MND community. During the roadshows, people will be able to hear more about the work of the Association and ask questions.

Finally, a note regarding the upcoming trustee elections which are crucial to ensuring the smooth running of the Association. Please look out for ballot papers in May. I hope to see some of you online at our AGM on 26 June, where our new trustees will be announced, along with a review of the achievements of last year.

# Leave your lasting legacy

## It's easier than you think

**You have the power to make a profound difference to people affected by motor neurone disease. And it's easier than you think.**

Legacy gifts are crucial to the MND Association's vital work. They fast-track development of cutting-edge technology, accelerate pioneering research and empower our vital support services. By including a gift in your Will to the MND Association you'll be directly helping us improve the quality of life for people affected by MND – no matter the amount you choose to leave.

£100 could buy a voice amplifier for someone experiencing communication issues, or a blender to make eating easier for a person with swallowing difficulties. These aren't just items – they're vital tools to help someone living with MND maintain their independence for as long as possible. What's more, you can play a pivotal role in our mission to realise a world free from MND.

£1,000 could pay for a detailed DNA analysis of someone with MND to help us get a better understanding of the disease. £2,000 could pay for the technology allowing one of our expert researchers to delve into complex data that can advance our mission to find a cure.

Step by step, every gift gets us closer to a world free from MND and ensures



people affected by the disease have the care and support they need.

Will you make your legacy count? By leaving a gift in your Will to the MND Association, you're helping to make the next breakthrough in care and research possible. It's one step that you can take today that will have a transformative impact in the future.

**Discover how you can make a lasting difference to people affected by MND and request your free *Gifts in Wills* guide today via our website [www.mndassociation.org/wills](http://www.mndassociation.org/wills) or call the Legacy team on 01604 611799.**

## "I decided this had to be the time"

### Vic uses the Association's free Will service



**Vic Fell recently claimed her free Will as a supporter of the MND Association. Sharing what motivated her to finally get around to making a Will, Vic said: "Like many people I put off writing my Will. I thought to myself, when I buy a house I'll get a Will, and then I thought, when I have a child, I'll get one then. I've had two kids now and decided this has to be the time!"**

"The Association's free Will service was easy and simple and although there was no obligation to leave a gift, I decided to include a small donation to the MND Association to cover the cost of my Will and to provide them with a stronger chance of finding a cure and helping people with this horrible disease."

Tick another thing off your to-do list, like Vic. Claim your free Will today, or find out more about how our free Will service can benefit you by visiting [mndassociation.org/free-wills](http://mndassociation.org/free-wills)

# “My stand against MND will never end”



Receiving an MND diagnosis at the age of 37 left Sam Perkins grieving for the active life he shared with his wife Emma. With a love of country walks and 40 triathlons, including two iron men competitions, under his belt Sam had to come to terms with living in a body that would no longer do the things he loved. Refusing to give up, Sam decided he needed a focus. He found that focus in a University of Nottingham laboratory, as he explains in his own words.

**I was at the GPs following an array of strange symptoms. I was relieved to hear ‘it’s not MND, you’re too young’. I’d wondered about MND, while very much hoping it was something else.**

Six months later I’d deteriorated hugely and was admitted to hospital with respiratory issues. This was quickly diagnosed as pneumonia. I ended up in intensive care where a neurologist did some tests. Shortly after this my family came to my bedside and my neurologist told us it was MND. Despite having read about MND, my first reaction was disbelief. I’d always had this feeling of invincibility and in that moment it had shattered.

Having my life expectations, dreams and ambitions altered so dramatically made it extremely difficult to think about the future - let alone plan for it. The list of things I could no longer do became endless. I’ll never run, pick up my nieces, properly laugh, drive, be alone, cycle or swim again. Once the news settled I realised I had a choice. I could be sad and bitter about the cruel hand life had dealt me, or I could make the most of the time I had left.

I chose to try and squeeze every last drop of life from the time available to me. Initially it was about spending as much time with my family and friends as possible to make some memories. But I needed more. I needed a purpose.



*Sam and Emma Perkins*

In January 2020 my wife Emma and I founded a charity, Stand Against MND, so that we could make a difference to the MND community and the future prospects for treatments.

After my diagnosis the offers of help and support which flooded in from family and friends gave me a great deal of comfort. We decided to harness that goodwill and turn it into cash for research. The biggest proportion of the money we’ve raised has been invested in the work of Professor Robert Layfield’s team at the University of Nottingham labs at the Queen’s Medical Centre. Supporting this work has given me such a lift.

It was quite a humbling experience

when I met the lead researcher of a project we were helping to fund. Hearing about the work they do and how Stand Against MND funding has made a difference brings a sense of pride and has strengthened my determination to do more. I have no expectation that a treatment or cure will be found in my lifetime. I actually find it quite liberating to have reached that acceptance. I’m not doing this for me, I’m doing it for the future so that people will have a less devastating journey than those of us today. I want people in the future to be given more hope.

My Stand Against MND will never end, this disease needs to be understood. Only then will the lives of the people it touches not be utterly devastated in the way that they are now.

**As well as previous donations to the MND Association, Sam’s charity recently donated £150,000 to invest in research.**

- £30,000 to University of Nottingham Astrocyte PhD project
- £50,000 to University of Nottingham Layfield project
- £32,500 to King’s College London Joe Reynolds PhD
- £37,500 to University of Sheffield Ergita Balli PhD

# Gaming inspired by granddad

## raises awareness of MND

**University student and YouTuber Tom Spoons, live-streamed his favourite video game for eight hours straight to raise money for the MND Association.**

With over 10,000 subscribers, Tom had completed two fundraising live-streams before, raising money for other charities, but this time it was personal.

Tom's grandfather was recently diagnosed with MND, so he wanted to do something to help. Tom, who goes by the name 'TXM-Tom Spoons' on YouTube said: "My granddad suffers every day from MND. This is a cause that is very, very personal to me. So any money raised was going to mean the world, but the fact that we've tripled our initial goal of £1,000 is absolutely crazy to me.



**Every single person who tuned into this stream, came out of it knowing what MND was, knowing the charity, and now forever having a link with it.**

"It has completely blown my mind. It is one of the greatest feelings I have ever had. Thank you to all of those who watched, and to all of those who donated. It means the absolute world. You don't know the butterfly effect it will have, but the idea it will really help someone like my granddad, that is amazing, that is life changing."

Tom live-streamed the football video



Tom Spoons during a livestream

game *Inazuma Eleven* for eight hours. The live-stream, which received 4,200 views, smashed the initial fundraising goal within the first half an hour. His international audience donated in eight different currencies.

Highlights of the stream included Tom receiving a cake from Dan Hunter, runner-up of last year's *The Great British Bake Off*, as well as Tom being candid with his fans about how the disease affects the family.

Moved by the response to his fundraiser, Tom said: "The success of the live-stream, it means everything. For both

my grandma and granddad, to them, it is unbelievable. They are absolutely over the moon with it, because it is a charity my family are contacting for support. More people should know about MND because it is such a horrible condition. And it is one people don't often know the full extent of."

Tom is keen to continue to use his role as a YouTube influencer to raise both money and awareness, as he explains: "I think I would be stupid to not use my platform for a cause that benefits the world and benefits people. At the end of the day, I am just a guy who sits here playing the football video game *Inazuma Eleven* and making videos about it. Few people have the opportunity to be an influencer, so to be able to use my platform to have these massive events for great causes and inspire people to support a cause they had previously never heard of, it is a no-brainer.

"Every single person who tuned into this stream, came out of it knowing what MND was, knowing the charity, and now forever having a link with it."

You can visit Tom's JustGiving page [www.justgiving.com/page/txm-inazuma-eleven](http://www.justgiving.com/page/txm-inazuma-eleven)



Tom Spoons raising a banner with Senior Community Fundraiser Tom Quirk

# Join us at EnCouRage UK 2024



PROMISE 3  
WE WON'T REST UNTIL  
EVERY DAY COUNTS

**MND EnCouRage UK is a two-day event bringing together early career researchers and people affected by MND. Now in its third year, EnCouRage UK has established itself as an important moment in the MND research calendar.**

This year's event takes place on 9 and 10 July at Staverton Park Hotel, Daventry, Northamptonshire. People affected by MND are invited to join us for the afternoon session on Wednesday 10 July to listen to talks about clinical trials and genetic research. There will also be opportunities to ask questions to our panel of MND researchers and clinicians.

A highlight of the programme is the 'Lightning Talks'. These give early career researchers a chance to share their research in 'bite-size' pieces while offering a snapshot of the huge range of MND research underway.

Registration opens on 23 April 2024. Spaces are limited and if demand is greater

than the places available, names will be entered into a ballot and drawn at random after registration closes on 31 May.



**If you have been a carer or currently a carer of someone living with or affected by MND, it's the perfect place to come and find out what's really happening.**

Jan Warren

Please visit our website to see the interim programme: [www.mndassociation.org/research/mnd-encourage-uk-2024/mnd-encourage-uk-mnd-community](http://www.mndassociation.org/research/mnd-encourage-uk-2024/mnd-encourage-uk-mnd-community)



Images taken at last year's event

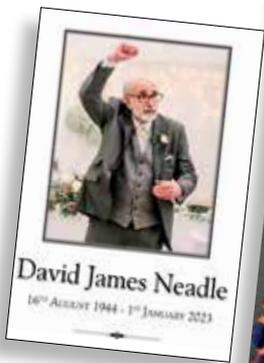


Dr Rick Nelms, MND Patient Fellow who is living with MND speaking last year

# “We want other families to have the time to make memories”

**Despite experiencing symptoms for 18 months, David Needle, a much-loved dad and grandad, received his MND diagnosis just eight days before he died. David's daughter Jess Davey shares how the delayed diagnosis affected the family and what they're doing to prevent other families from going through the same thing.**

There were so many things we would have loved to have done for Dad, had we known he had MND. But we only got a confirmed diagnosis eight days before he died. If he had received his diagnosis earlier, it would have given us time together to visit all the places he loved. Instead the grandchildren visited those places and FaceTimed him, so he could still see them.



**We're determined to raise money and awareness so that no family will have to go through what we did. We especially want to raise awareness among GPs, so that they're alert to the symptoms of MND.**

Dad was a very hard-working family man. Gentle, kind and intelligent, he was a scientist. Dad was rarely at the GPs, until the day he had a fall. After that, he started to lose weight and muscle mass. Looking back now it's clear it was MND. He'd repeatedly go back and forth to the GPs but never received a referral to a neurologist.

At one point it was suggested he'd had a stroke, during his time living with MND. After months of getting nowhere, Dad went to a private neurologist who suspected MND, and arranged for him to have nerve testing.

Three days before Christmas, Dad became very unwell. Choking and chesty, he was admitted to hospital with Covid and aspiration pneumonia. Dad was rapidly going downhill. While he was in hospital the neurologist emailed my sister with the confirmed diagnosis of MND. Finally we knew what was wrong.

We managed to get Dad home for his final Christmas. He died New Year's Day with his beloved wife Judy, and all his family by

his side. After Dad's funeral, my brother Jamie came up with the idea to run the 23 miles from Dad's birthplace to his final resting place at the natural burial ground. The idea grew and soon the whole family got involved.

All the children and grandchildren started off from Dad's birthplace on a route through all the significant places of Dad's life. People joined for different stretches, but everyone crossed the finish line together, including Mum. It was such a beautiful way to pay tribute to Dad. He would have loved that we were all together. Organising the day helped us in our grief process. Dad used to say 'turn a negative into a positive' so that's what we're trying to do. Fundraising has become a way of life for the family.

We had such little time to adjust to Dad's diagnosis. There was no time to consider his final wishes. We spent our last week in crisis. We don't want other people going through what we did. We want other families to have the time to make memories.

We're determined to raise money and awareness so that no family will have to go through what we did. We especially want to raise awareness among GPs, so that they're alert to the symptoms of MND. We've found the *MND Pathway* is a great way to do this. We're also delighted to have raised over £5,600 for the MND Association. We'll continue to do whatever we can in Dad's memory. He was a special man and this is a positive way to pay tribute to him.



# 'Heartfelt thank you' to rugby

**HRH The Princess Royal met rugby league fans who have supported the MND Association over the last four years, at an afternoon tea to mark their incredible achievements.**

Our Royal Patron, The Princess Royal was guest of honour at the special Thank You event at Leeds Rhinos' AMT Headingley Stadium on 28 February.

Her Royal Highness spoke to around 80 guests, all of whom have been inspired to volunteer or fundraise by Rhinos' legend Rob Burrow CBE and his former team-mate Kevin Sinfield CBE. Collectively they have raised around £8.2million for the MND Association.

Rob Burrow was diagnosed with MND in December 2019. Since then, he and his family have shared their story across multiple channels to raise awareness of motor neurone disease and to encourage support of MND charities. As a result, clubs, players and supporters from across both rugby codes have fundraised for the MND Association.

Chief Executive, Tanya Curry, introduced The Princess Royal to guests. She said: "So many people within the rugby community have followed Rob's journey and his friendship with Kev, and been moved to show their support by helping us to raise awareness of this brutal disease, and donating to the MND Association.

"This event was our chance to say a heartfelt thank you for everything they have done. And we were delighted that the Princess, who has been our Royal Patron for the last 16 years, was able to deliver that message of gratitude alongside us."

Guests enjoyed a backroom tour of AMT Headingley Stadium, before sitting down for afternoon tea. They were joined by The Princess Royal who, after meeting guests, gave a speech thanking everyone for their efforts. Eleanor Dalley, who has MND, also gave her thanks to those in the room.

Also in attendance were Lord Lieutenant of West Yorkshire Ed Anderson CBE, Lord Mayor of Leeds Al Garthwaite and High Sheriff of West Yorkshire Zulfi Karim, accompanied by Saira Karim.



Tanya Curry Chief Executive and Usman Khan Chair of the Association pictured with the Burrows family



Sally Hughes, Director of Services and Partnerships



Tanya Curry, Chief Executive of the MND Association



The Princess Royal chats to Rob Burrow CBE

# fans for raising over £8million



This event was our chance to say a heartfelt thank you for everything they have done. And we were delighted that The Princess Royal, who has been our Royal Patron for the last 16 years, was able to deliver that message of gratitude alongside us.



Neil and Kim Sandford



Zane and Jordan Pilkington



Chief Executive Tanya Curry with Rob Burrow CBE



Ian Campbell and his wife June share a joke with Denise Davis, Head of Community Fundraising



Rachael and Ian Flatt



# “Sometimes, just visiting the page it almost feels like part of him is still here”

**Kirti Thakrar’s husband, Harish, died from MND in 2021. Kirti and her family, including her and Harish’s two sons and daughters-in-law, set up a Tribute Fund in Harish’s memory. The Tribute Fund is a special place for their family and friends to remember Harish and see their incredible fundraising efforts in one place.**

Kirti describes her husband as ‘a true gentleman, very intelligent, very kind, and compassionate’. Kirti said: “He’d always done community work right up until about a few months before he died.”

Their daughter-in-law, Sheenal said: “He was always there for anyone who needed help.”

Harish’s older brother died from MND 20 years ago. From that moment, Harish and Kirti became members of the MND Association. Kirti said: “I think because it was quite important to Harish, we’d already started fundraising while he was alive.”

After Harish’s diagnosis in 2017, his family took him on a number of pilgrimages to India.

Harish’s daughter-in-law Sita said: “That was really, really special for us, and some of the best memories we have of him.”

Kirti and Harish had also visited their local MND drop-in centre. Kirti said: “They were only a phone call away. I know that they’re a lifeline to people suffering with this cruel disease and their families.”

The online page set up for Harish’s Tribute Fund is a place for family and friends to gather and share their own stories of Harish, as well as light candles and upload treasured photos.



**I think he’d be very proud of the fact we’re collecting money for research because he wanted a cure for this disease.**

His son Avnish said: “You actually learn about other people’s perspectives of Dad, perhaps stories that we’ve never heard about. It’s amazing to see the number of people from such diverse backgrounds, messaging, donating, and sharing lovely stories of Dad.”

The Harish Thakrar Tribute Fund has raised £22,613.19.

Kirti said: “I think he’d be very proud of the fact we’re collecting money for research because he wanted a cure for this disease.”

**You can set up a Tribute Fund in memory of a loved one today, visit [www.mndassociation.org/tribute](http://www.mndassociation.org/tribute)**



The Thakrar family sharing photos of Harish. From left to right: Sita, his daughter-in-law, Avnish, his son, Kirti, his wife, Kunal, his son and daughter-in-law, Sheenal

## “Campaigning really works” says South-East Wales Branch

**The MND Charter calls on local councils across the UK to adopt a list of pledges that will help them positively influence the lives of people living with MND in their community. Thanks to the incredible efforts of our campaign volunteers, almost 100 councils across the UK have adopted the MND Charter.**

The efforts of Judith Rice, campaign volunteer and a member of the South-East Wales Branch of the MND Association have seen Newport City Council, Aneurin Bevan University Health Board and Caerphilly County Borough Council all

adopt the *MND Charter*. Judith explains in her own words her process for engaging local councils.

“First, I contact the appropriate people at the council. I’d suggest reaching out to people at the top, such as the Leader of the Council, and introduce yourself by email. Ask to set up a meeting with the Leader and other council cabinet members. In the meetings I talk about the history of the Association, the characteristics of MND, and notable people living with MND such as Rob Burrow. I then introduce the *MND Charter* and ask them to pledge their support.



Judith Rice pictured second from the left

Campaigning really works. It’s not as hard as it may sound – and you’ll be making a positive difference for people living with and affected by MND.”

**Want to get involved in campaigning for your council to adopt the MND Charter? Visit [www.mndassociation.org/mndcharter](http://www.mndassociation.org/mndcharter)**

# Tofersen update

## Drug unlikely to be approved for England



**Our first concern is for those families which have already been devastated by this disease and for whom tofersen provided hope.**

Dr Brian Dickie MBE, Director of Research Development at the MND Association

**In September 2021, researchers investigating the effectiveness of the drug tofersen on people with an inherited form of MND found it slowed progression if taken over a 12 month period.**

Since then, tofersen, under the name Qalsody, has been approved by the Food and Drug Administration in the USA and recommended by the European Medicines Agency for the treatment of people with MND who have an alteration in the SOD1 gene.

But in March, a decision by the National Institute for Health and Care Excellence (NICE) made it highly unlikely that tofersen will be approved for use in England.

NICE announced the drug would be

appraised through the Single Technology Appraisal (STA) route rather than the Highly Specialised Technologies (HST) route.

Tofersen is a precision treatment developed by Biogen for the 2% of people with SOD1 MND – around 100 people in the UK at any one time. In England, it is standard practice to appraise treatments targeting rare diseases (affecting less than one in 50,000 people) through the HST route. NICE's STA criteria means tofersen would fail, making it unlikely Biogen will submit an application.

Director of Research Development at the MND Association Dr Brian Dickie MBE said: "This is an extremely disappointing decision by NICE based on outdated

understanding of MND. Our first concern is for those families which have already been devastated by this disease and for whom tofersen provided hope.

"We also have an eye to the future – millions of pounds are being ploughed into innovative research which targets rare diseases, including MND. Decisions like this one, by NICE, risk that investment – why would funders support research if successes are likely to be blocked during the regulatory process?"

The MND Association is now working at speed, with the MND Clinical Study Group, other charities and its networks in a bid to encourage NICE to reconsider its decision.

More information will be shared on our website.

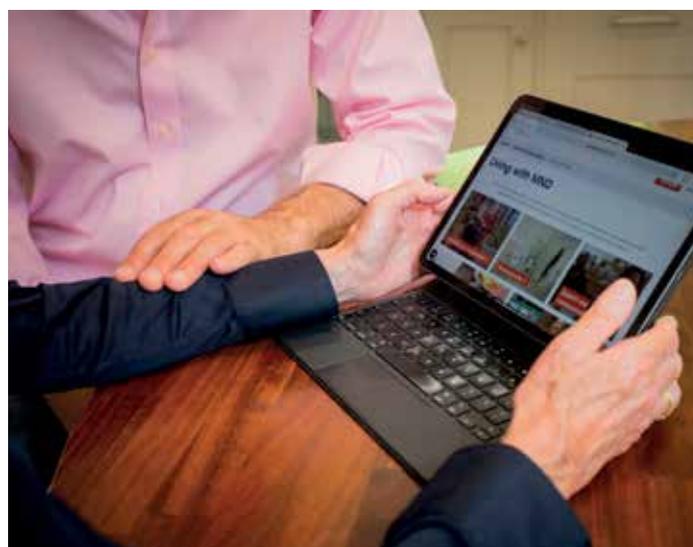
## My MND My Needs

### Thank you to respondents

**Thank you to everyone who took part in the Association's My MND, My Needs survey.**

More than 900 people with MND from across England, Wales and Northern Ireland took the time to complete the survey, which covered a range of topics including health, wellbeing, support received since diagnosis and the impact of MND on day-to-day life.

The process of analysing responses is underway. The findings will help us identify our future priorities and work towards improving support for people affected by MND. Look out for further updates in future editions of *Thumb Print*, or on our website.



# Largest ever #TeamMND to take on the Cardiff Half Marathon

**As part of our new partnership with Run 4 Wales, we'll have more people running the Cardiff Half Marathon this year than ever before. Over 60 #TeamMND runners will take to the streets on Sunday 6 October and staff, volunteers and supporters will be there to cheer them on.**

Kate Bryon, Chair of the Cardiff and Vale Branch said: "The MND Association Cardiff and Vale Branch is very excited to be partnering with Run 4 Wales for the Cardiff Half Marathon. It's the perfect opportunity to showcase our magnificent city to thousands of runners while raising much-needed awareness of MND. This is the first time we've had a presence in the runners' village, so it'll be great to meet and say thank you to our #TeamMND runners and maybe even recruit a few more volunteers for our branch!"

Matt Newman, Chief Executive at Run 4 Wales said: "We're really pleased to be working with the MND Association as our Charity of the Year for 2024. It's a particularly poignant charity for us at Run 4 Wales as several members of the team, myself included, have experienced the devastating impact motor neurone disease has on families.

"We're wholly supportive of the



Kate Bryon pictured left with Karen Williams

incredible work the MND Association does and we hope that in providing packages for runner spaces in our events – which make more than £4 million for charities each year – combined with team fundraising activities, we can help to make a difference."

The partnership also includes three 10K running events which we're excited to add to our 2024 running calendar; Cardiff 10K, Cardiff Bay 10K and Porthcawl 10K. You can find out more and register

for these events by visiting [www.mndassociation.org/cardiffhalf](http://www.mndassociation.org/cardiffhalf)

## **Brecon Caregg Cardiff Bay 10K**

Sunday 19 May 2024

## **Ogi Porthcawl 10K**

Sunday 7 July 2024

## **Cardiff Caerdydd 10K**

Sunday 1 September 2024

## **Cardiff Half Marathon**

Sunday 6 October 2024

## Rugby fan Eddy runs a half marathon a day inspired by the man 'with the heart of a lion'



**Eddy Eggleton is a huge rugby fan and was inspired to raise funds for the MND Association following rugby legend Rob Burrow's devastating diagnosis.**

Eddy said: "The smallest man in Rugby League with the heart of a lion, Rob would bring down men 6ft 6in with his own two hands. That, for me, is the reason I run to raise funds for the MND Association."

Eddy took part in the 2023 Rob Burrow Leeds Marathon, and signed up to do it all over again in 2024. But for Eddy that was not quite enough. He decided to take on an extra challenge to run a half marathon every day in January.

It was wet, it was cold and it was

tough. Some days he ran on a treadmill, but every day he smashed his miles and every day the money increased. By the end of his challenge Eddy had raised over £2,000. Eddy knew it wouldn't be an easy challenge, but he believes it's nothing compared to what those living with MND go through every day.

Raising money for the Association has got even more personal for Eddy after recently hearing the sad news that two of his family members have been diagnosed with the disease. He said: "As someone who has seen first-hand the devastating effects of MND, I am committed to doing my part in improving access to care, research and campaigning for those affected by this disease."



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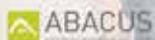
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# Meet the professionals: Wheelchair services



**MND can make muscles weaker and tired, which can make it hard to move and walk. Eventually, most people with MND will need a wheelchair.**

Having the right wheelchair is crucial, as it helps people move around comfortably and safely. The right wheelchair can provide proper support for weakened muscles and help prevent further complications such as pressure sores. It also promotes independence and improves the person's quality of life by allowing them to continue engaging in daily activities despite their mobility challenges.

Lynne Hills and Maggy Hevicon are both wheelchair therapists who work with the MND Association's Wheelchair Support Service to help improve the provision of wheelchairs for people with MND. We asked Lynne and Maggy to answer five questions about their work.



Lynne Hills



Maggy Hevicon

If you have any questions or experience any problems accessing a wheelchair, please contact the MND Association's Wheelchair Support Service by emailing [wheelchairqueries@mndassociation.org](mailto:wheelchairqueries@mndassociation.org) or contact MND Connect on 0808 802 6262.

## **QUESTION 1: How can your role support people with MND and/or their carers?**

- We work with wheelchair services both locally and nationally to improve pathways to provide timely access to assessment and provision.
- We support people with MND in their wheelchair provision and offer advice regardless of where they live. This includes information on the types of chairs available.
- Working with manufacturers we help shape the development of products to meet the needs of people with MND. We also work with manufacturers on a system to prioritise and fast track orders.
- As therapists we clinically support two MND care centres in London, but we support other care centres and networks across the country as required.
- We are always researching and exploring new technologies that may be useful for people with MND.

## **QUESTION 2: What are some of the challenges you face as a wheelchair therapist?**

- Timely assessment and prescription of suitable equipment.
- Anticipatory prescribing – it's important to have a wheelchair that meets current and longer term needs.
- Variations in service provision across the country.
- Environmental challenges – many homes are not suitable for certain pieces of equipment due to size, access or other limitations.

## **QUESTION 3: What is the most rewarding part of being a wheelchair therapist?**

- Affording individuals the opportunity to be as independent as they can be with their mobility and day-to-day life.

## **QUESTION 4: Do professionals in your specialism work closely with another discipline?**

- Yes. It is essential we work in partnership with the wider community teams.

## **QUESTION 1: How can people access support from wheelchair services?**

- Every area has a local wheelchair service which is responsible for the assessment of an individual's wheelchair and seating needs. Usually first referrals need to be made via a health care professional or GP. Thereafter, the client can contact the wheelchair service to request a review, as required.

## **How to find out more**

For people with MND: Information sheet 11C – *Equipment and wheelchairs*

For professionals: Information sheet P2 – *Wheelchairs for MND*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

# What do I do next?

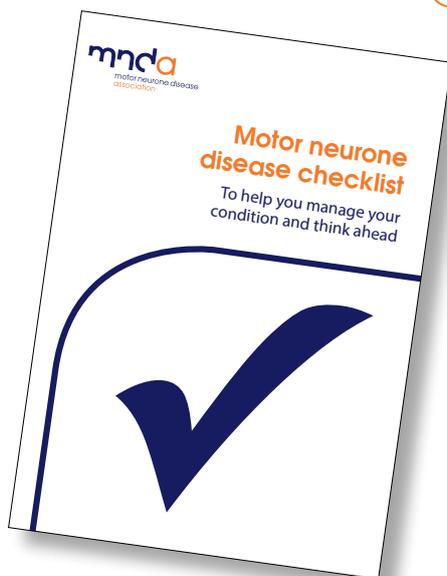
## Adjusting after an MND diagnosis

**It can take time to adjust after the shock of an MND diagnosis, but when you begin to think ahead, how do you even know what questions to ask?**

When Alex was told he had MND he felt numb, as he explains: "In that moment, it doesn't feel real. I didn't have a breakdown or cry or anything like that. I just felt really numb. I think with MND, if you're at the start, despite what you might have read online, or other people you have seen, you really don't know what your journey is going to look like."

Even after the initial shock, it's not always easy to start asking questions. Sue, who is living with MND, said: "With MND, professionals want you to visualise what's ahead, and think and plan. 'Futurise' is the buzzword. I understand why, but I do find that hard."

Our *MND Checklist* can help you find the right questions. It is a short booklet that uses prompts to help you think



about your care needs, with space to write notes. Feedback from our MND Care Centres and Networks have shown that people find the checklist easy to use and helpful. Some felt less overwhelmed and nervous, as the questions encouraged

them to think in ways they may not have done otherwise. The notes section also helped their health and social care professionals to steer clinic appointments in a more tailored way.



**If you're at the start, despite what you might have read online, or other people you have seen, you really don't know what your journey is going to look like.**

We have recently updated the *MND Checklist*, which is still available in print form. We have also created an online version, for quick access on screen. You can find the online checklist at [www.mndassociation.org/mndchecklist](http://www.mndassociation.org/mndchecklist)

## New Regional Roadshows



**Our new Regional Roadshows are a fantastic opportunity for members to hear more about the future direction of the Association and our priorities for helping people with MND.**

Importantly, they are also a chance to meet with, and hear from, Association staff, trustees, members and volunteers to share ideas and help shape future plans.

Our first Roadshow was held in Northern Ireland earlier this month, and our Wales event is just around the corner, taking place on Thursday 9 May.

There is still time to register for Roadshows in England:

- **York** - Tuesday 14 May
- **London** - Monday 20 May
- **Exeter** - Friday 24 May
- **Northampton** - Tuesday 18 June

For more information visit [www.mndassociation.org/events/regional-roadshows](http://www.mndassociation.org/events/regional-roadshows) or contact [conference@mndassociation.org](mailto:conference@mndassociation.org) or 01604 611844.

# Celebrating the contribution of women to MND research



Charlotte Gale



Dr Emily Carroll



Dr Rebecca Saleeb

**To find a cure for MND, we need the brightest scientific minds on the job. Increasingly women are playing a crucial role at the forefront of MND research, working towards a better future for people with MND. To mark International Day of Women and Girls in Science, we are celebrating the work of three women we fund.**

Charlotte Gale, a PhD student at the University of Sheffield, is using fruit flies to uncover more about the transport of materials in cells in MND. Charlotte said: "It seems like in our fruit flies there is a problem in moving bits of the cell that are needed for maintenance from one end to the other. When cells get old and start falling apart, or they need things repairing, if those bits that are needed can't get down the cell, then that might be contributing to the cells dying. We're looking at a number of different ways that we might be able to rescue that effect in the flies such as gene therapies or different drugs."

Dr Emily Carroll, a pre-fellow based at the University of Oxford, is looking to repurpose existing drugs to treat MND.

She is testing drugs on cells in the lab that have a faulty gene linked to the development of MND. Emily said: "I hope we can identify drugs that are capable of rescuing MND-associated traits in the different model systems that we have in the lab. If we can see that, it would be great to take those drugs forward, to look at whether they also show beneficial effects in mouse models of MND and then eventually investigate them in a clinical trial."

Dr Rebecca Saleeb, a Research Fellow at the University of Edinburgh, is searching for proteins in biological fluids of people with MND. Rebecca said: "I want to extract TDP-43 or FUS, proteins that we know are involved in the development of the disease. I then analyse them using cutting-edge imaging technologies that can assess not only whether they are there, but also if they are irregular, if they form clumps and if they have certain changes that we can link with MND." These biomarkers may act as 'flags' of disease and could be used to develop diagnostic tests in the future.

Rebecca would like to see more

women consider science as a career and progress to senior positions. She said: "I have generally felt very welcomed and supported by the people around me, but it can be tough being a woman in science. There's still progress to be made in supporting women to stay and make it work for them."



**I have generally felt very welcomed and supported by the people around me, but it can be tough being a woman in science.**

Currently, half of the non-clinical fellows and nearly two-thirds of the PhD students we fund are women. We are proud to support talented women to build their careers in MND research. The MND Association funds female researchers at all stages of their careers who are carrying out research into different aspects of MND, from understanding the disease through to finding new treatments.

# Association seeks resolution to riluzole access challenge

**The MND Association has been working hard to understand and resolve the issues some people have faced accessing riluzole, the only licensed treatment for MND.**

Shortages of the generic tablet form of the medication were first reported at a small number of pharmacies in England last September. Despite initially receiving reassurances from the medicines supply team at the Department of Health and Social Care (DHSC) this was a short-term issue, the Association continued to receive reports that people were struggling to access the drug.

The situation was worrying and frustrating for the MND community, and complex for the Association to unpick. As well as maintaining contact with the DHSC, Association teams organised conversations with Community Pharmacy England, raised concerns through the All-Party



Parliamentary Group for MND, submitted a Parliamentary Question, and our Chief Executive Tanya Curry wrote to the Secretary of State for Health and Social Care, Victoria Atkins, urging her to provide more clarity on the shortages. We also engaged with local and national media to highlight the issue, securing coverage in the Daily Express, Guardian and Independent.

Through these discussions, it became clear the shortages began when manufacturers struggled to source the active pharmaceutical ingredient to make riluzole, which resulted in some pulling out of the UK market. This reduced availability of the drug and resulted in people experiencing difficulties with pharmacies fulfilling their prescriptions.

Actions were taken by organisations across the supply chain to resolve the issue and there has now been a reduction in the number of reports from people who have struggled to have their prescriptions fulfilled.

We will continue to share any reports we receive with the DHSC and Community Pharmacy England, while also focusing on seeking reassurance from all those involved that the correct systems are in place to avoid this worrying situation arising again.



## CARE INFORMATION UPDATES

**Here are the latest care information resources now available.**

### **Inherited MND and gene testing**

Our new booklet explores genetic counselling and genetic testing for people who have a family history of MND.



### **Advance care planning (ACP) for MND**

This involves discussing, documenting and respecting the wishes and preferences of people with MND



regarding their future care. ACP involves making informed decisions about personal, legal and financial issues as well as future healthcare. Our booklet includes information and practical strategies to help professionals effectively support advance care planning for people with MND.

### **The following information sheets have been updated.**

- 2C Primary lateral sclerosis (PLS)
- 2D Progressive muscular atrophy (PMA)
- 7A Swallowing difficulties

We have also revised the following resources for health and social care professionals.

- Occupational therapy for MND
- MND – a guide for social care services

You can see all of our resources at: [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or order printed copies from MND Connect helpline: 0808 802 6262, [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)



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

### **Would you like to help with our information development?**

We work alongside people with MND or Kennedy's disease, and their carers, to develop and improve our information.

We have lots of work planned for 2024. If you would like to get involved, you will have opportunities to feed into a range of different content and formats. To find out more contact [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

# Prospective MPs urged to champion MND



Ahead of the next general election the MND Association has published its manifesto, setting out how the next UK Government can improve the lives of people living with MND.

The manifesto has been informed by the experiences of people with MND and their carers. It's a detailed plan that focuses on five key areas to ensure everyone living with MND can access the support they need, when they need it.

Urge your candidates to champion MND if they become an MP



## The five key areas for action:

### 1 Accessible homes

Many people with MND are trapped in inaccessible homes because councils are failing to provide sufficient support. We recommend councils introduce a fast-track process for people with MND, remove financial assessments for disabled facilities grants and maintain a register of accessible homes for people to move into.

When James Smith was diagnosed with MND in 2021, he was only able to make the necessary adaptations to his house because of family support. James said: "I have a mortgage so there seems to be less help. I can't get a council house, I can't afford to rent somewhere, the only option I did have was to renovate it. If it wasn't for a family member who helped us out, we wouldn't have been able to get the adaptations done."

### 2 Access to treatments

While it's positive there are now promising medicines for MND in the pipeline, regulatory barriers could prevent people with MND accessing them in a fair and timely way. Drug licensing and regulatory bodies in the UK are often too slow in assessing treatments, and their processes are not always uniform, resulting in confusion around how patients can access treatments quickly.

We are calling on the next Government to continue to invest in MND research to enable more discoveries of effective medicines. We are also asking the Government to ensure regulatory processes allow for fair and equitable access to new medicines for people living with MND.

### 3 Cost of living

Managing and living with MND is costly. Our research has discovered that, on average, people with MND spend £14,500 a year meeting the full costs of the disease. Expensive housing adaptations and using powered equipment puts huge pressure on household income. Energy bills are typically higher for people living with MND - on average a person can spend up to £600 a year just on using equipment to manage their condition.

We are calling on the Government to deliver targeted support to help households cope with energy costs during the coming winter. We also want them to consult on the delivery of long-term support for energy costs such as the Energy Social Tariff, in line with commitments made by the present Government in 2022 and 2023.

### 4 Social care

Social care in the UK is in crisis.

Chronically underfunded and with a severe staffing shortage, this is leading to significant delays and a lack of provision for people with MND. We are urging the Government to do more to ensure social care reform can benefit those who need it most, including people with MND.

We recommend the Government commits to sufficient and sustainable long-term social care funding, publishes and implements a social care workforce strategy and agrees to funding reform to prevent households being hit with catastrophic costs as a result of their care needs.

### 5 Support for MND carers

Due to the strict eligibility criteria for Carer's Allowance, just one in ten carers of people with MND report that the Allowance meets their needs as carers. For those who do receive it, it doesn't go far enough, especially if they've had to stop working. A respondent to our *Carer Survey* said: "I've had to give up work to care for my husband and now only receive carer's allowance."

We are calling on the next Government to increase the rate of Carer's Allowance to a level that reflects the value unpaid carers offer. We are also asking for a review of the strict eligibility requirements, such as removing the earning threshold.

# MND carers invited to take part

– peer-to-peer support programme



PROMISE 5

WE WON'T REST UNTIL  
NO ONE FACES MND ALONE

**Research supported by the MND Association and Marie Curie is aiming to understand the impact of a virtual peer support programme on the wellbeing of carers for people with MND.**

Providing care and support for someone with MND can be physically and emotionally exhausting. If the person they're caring for is dependent on assistive technology, this also requires the carer to learn how to operate medical devices, train others, and communicate with a range of healthcare professionals.

Professor Louise Rose and her team at King's College London have developed an online peer support programme for carers of people with MND who are technology-



Professor Louise Rose

dependent or at risk of becoming so. The study will test how a 12-week programme with peer supporters, who've previously cared for someone with MND, can affect carer wellbeing. Trained volunteers will take on the role of a peer supporter to provide support to carers through an online app (similar to WhatsApp).

Professor Rose said: "We designed this programme to create a safe space for caregivers to talk about their needs and experiences, as well as to receive practical information on the issues they're dealing with on a daily basis from others who've been through a similar experience."

Chris Bennett, Head of Regional Services and Partnerships at the MND Association said: "We know informal carers are at increased risk of psychological distress and it's important they're given support to carry out their role. Improving the mental well-being of carers is a key priority and we are delighted to fund a study that looks into a way of supporting this vital resource."

The study is recruiting participants now. If you are an informal carer and would like to get involved, please contact [peersupport@kcl.ac.uk](mailto:peersupport@kcl.ac.uk)



## Renovating dolls houses helped grieving friends

**Julia Scott has been using an unusual way to raise funds for the MND Association. Along with her friend, Karen Symons, she has been renovating dolls houses. The unique fundraising venture started shortly after Julia's dad Graham died of MND.**



Julia said: "I had just lost my dad to MND and my friend had just lost her mum to pancreatic cancer. We were each grieving but found the work of planning, restoring, and creating a new tiny home for others to enjoy, a therapeutic, soothing, rewarding process."

"Watching Dad go from the strength of a former rugby player who had always kept himself fit to gradually fade away was so cruel. He continued to be the generous gentleman he'd always been, accepting the increasing amount of help he needed with a grateful smile and thumbs up when he could no longer speak."

Julia's family received support from the MND Association. She said: "Dad's connection with the MND Association Nottinghamshire Branch came about three months after his diagnosis, in the



Julia and her Dad

form of monthly meetings both he and my mum attended. The Association granted a substantial amount of money towards the external ramp which he needed to access the house in his wheelchair, and they were both so grateful for this help."

To see more of Julia's incredible renovations visit [www.instagram.com/dollshousesrelieved](http://www.instagram.com/dollshousesrelieved)

# Volunteering is a rewarding experience

## 95% of people surveyed agree

**Our volunteers play a vital role in the fight against MND, so we were delighted to hear that so many enjoy their volunteering experience with us.**

Our volunteer experience survey gives us valuable insights into the experience of volunteering at the MND Association, helping us to understand what we do well and what we could do better. We received almost double the number of replies in our most recent survey than in the last full survey in 2021.

- **Over 95% of volunteers feel that volunteering for the MND Association is a rewarding experience.**
- **Over 90% would recommend volunteering with the Association to others.**
- **Over 90% felt they were able to make a positive difference to people living with MND.**

Head of Volunteering, Matthew Cobble said: "We are committed to providing an excellent experience for volunteers at the Association and I'm delighted so many volunteers feel

that the time they give is a rewarding experience. We saw improvements in almost all aspects of the survey compared with two years ago, including feeling connected to the Association and being supported by Association staff.

"This feedback helps us to understand what is working and where we need to improve. We have already started to look at how we can implement changes based on volunteers' suggestions to make the experience even better."

Over 80% of respondents said that they 'felt valued and appreciated' by the Association. To further improve on our work in this area, this year's Regional Roadshows (page 27) will provide an opportunity to recognise successes across the regions. We hope to see many volunteers at the Roadshows so we can thank them in person for everything they do for the MND Association.

**If you are interested in volunteering visit [www.mndassociation.org/get-involved/volunteering](http://www.mndassociation.org/get-involved/volunteering) to find opportunities in your area.**

## London Winter Walk

### #TeamMND walk over 2,000 miles

**Josefina Bugh and her friends joined 118 members of #TeamMND to walk through the streets of the capital for The London Winter Walk. Like many on the walk, Josefina's reason for taking part was deeply personal.**

Josefina's husband James was diagnosed with MND last year, so



Josefina Bugh and her husband James



Taking part in The London Winter Walk

she wanted to do something for the Association. She said: "The walk was incredible. It felt really cathartic walking along the river, talking to some of my longest-standing friends and just thinking about life, being away from home and day-to-day things that need my attention.

"I wanted to do something in return for the MND Association, to celebrate and draw focus on what an incredible charity it is and how much it's helped us as a family. James is thriving with the support he receives and is at the stage now where he is starting to use his iPad (on loan

from the MND Association) and voice box much more now."

Between them #TeamMND walked over 2,000 miles and raised more than £40,000. The London Winter Walk was the first event in the Ultra Challenge Series for 2024. The series of 17 events takes place in locations across the UK including the beautiful Jurassic Coast and Lake District. The events are suitable for varying abilities, with distances ranging from 10km to 100km. For more information or to find an Ultra Challenge to suit you, visit [www.mndassociation.org/ultra](http://www.mndassociation.org/ultra).

# The Steve Jobar MND Handicap Hurdle

raises over £100,000



John Francome MBE British Champion jump jockey, speaking at the event



What an extraordinary day, both positive, generous and fun. If you could bottle the feelings coming from all in the room I think we would have a cure tomorrow. I may not be functioning right but it was still one of the best days of my life

Steve Jobar

Francesca Alport

**Former National Hunt jockey Steve Jobar, was diagnosed with Bulbar MND in April 2022. A jockey for 20 years, Steve won 135 races including the 1980 Triumph Hurdle at Cheltenham. Since his diagnosis, Steve and his wife Dottie have worked tirelessly to raise both awareness and money to support others living with the disease, and their families.**

Steve has now lost his speech, his ability to swallow has deteriorated, and he's lost strength over the last few months. But despite all this he and Dottie remain positive. Steve said: "I think it is a good thing that people realise what a horrible disease it is. No-one knows what happens, no-one says anything about the impact it has on your life."

Both Dottie and Steve have been keen to galvanise the racing community to support the MND Association and raise awareness, noticing the difference the rugby community has made. With the help of their friend Jonathan Powell, they decided to organise an afternoon fundraising event at Newbury Racecourse. They formed a planning committee which included Dottie's twin daughters Karen and Nicole, along with friends and representatives from the Reading and West Berkshire Branch.



Steve Jobar in his racing days

The Steve Jobar MND Handicap Hurdle was held on 22 March. Over 450 people from the racing community, along with friends, family and local business people supported the event. Guests enjoyed a champagne reception, a dinner hosted by Mike Cattermole and the main auction hilariously hosted by horseracing broadcaster, writer and commentator John Francome and Northern Irish Champion National Hunt racing jockey AP McCoy.

One lucky raffle player won a car while many more went home with incredible sporting memorabilia and artwork secured in the silent auction. The winning horse of the sponsored race was gowned in an MND Association branded horse rug to pose for photos. Steve presented the owner with a



Steve and his wife, Dottie

unique trophy sponsored by Dottie's son Nicholas Channing Williams, a professional showjumper.

The event raised more than £175,000 thanks to the hard work and determination of everyone involved in the planning, guests, sponsors and branch volunteers who held a bucket collection around the course. The funds will be split between MND research and the Reading and West Berkshire Branch, which has supported the family since Steve's diagnosis.

Steve said: "What an extraordinary day, both positive, generous and fun. If you could bottle the feelings coming from all in the room I think we would have a cure tomorrow. I may not be functioning right but it was still one of the best days of my life."

# Giant 8ft dinosaurs

## complete epic fundraising challenge



“  
It’s been quite an emotional journey. We can’t get over how many people turned up in the cold, wet and miserable weather. It was amazing.”

### Two friends from Lee-on-Solent walked 15,000 steps every day during January - wearing 8ft inflatable dinosaur costumes.

Graeme Lloyd and Tommy Russell made quite a sight in Gosport and Lee-on-Solent where they walked around eight miles a day to notch up the necessary steps.

The pair took on the month-long challenge to raise money for the MND Association in memory of Graeme’s mum Gaynor, who died from MND in 2019. The family then experienced more devastation when her sister (Graeme’s aunt) was diagnosed late in 2023. The MND Association provided practical support to Gaynor and her family during her illness as well as counselling services.

Graeme said: “In 2019 I ran the Manchester Marathon in the dinosaur costume and it got a lot of press attention. The MND Association organises a 15,000 step challenge every January. It’s a big challenge but I wanted to do something that would stand out and catch peoples’ attention. The costumes are 8ft, they blow in the wind and look quite funny so we thought we would wear



them – it’s grown out of all proportion since then.”

The pair’s endeavours captured the imagination of the local community. Graeme said: “Having members of the public just jump out of their car with their own dinosaur costumes and join us on walks was always pretty special. We have made some really good friends from that.”

Graeme and Tommy were invited by several local hostelrys to collect funds on behalf of the Association, which culminated in an epic 19-stop dinosaur pub crawl one memorable weekend. Around 60 people, young and old, joined them on a cold, wet day on their final walk along Marine Parade, many of them in dinosaur costumes.

With the challenge over, Graeme reflected: “It’s been quite an emotional journey. We can’t get over how many people turned up in the cold, wet and miserable weather. It was amazing.”

“Our original target was £500 but we have raised over £10,000 which is a staggering amount. It’s just nice to see people smiling. People find January a really hard month, and we have had lots and lots of messages from people telling us that this January has actually been quite fun. Just being able to put smiles on people’s faces while we are doing something positive has been great.”

Graeme received hundreds of messages from people saying how they have been affected by MND. He said: “It’s far bigger than people realise. There has been a lot of awareness raised by Rob Burrow, and Kevin Sinfield running his marathons, but I think there are a lot more people being touched by it locally that are now coming to light.”

Graeme hasn’t ruled out further fundraising, but he is adamant it won’t involve dinosaur costumes!

# The All-Party Parliamentary Group

**The All-Party Parliamentary Group (APPG) on MND is a cross-party group of MPs and Peers with an interest in MND. The purpose of the group is to increase awareness and understanding of MND among parliamentarians and to campaign for policy change across a range of issues that matter to people living with MND.**

In March, the group held its AGM and successfully re-formed for its 22nd consecutive year, which is an amazing achievement. Andrew Lewer MBE MP who has been involved with the group since he entered Parliament in 2017 was re-elected as the Chair, with Mary Robinson MP, Ian Byrne and Brendan Clarke Smith elected as officers. Over 30 MPs have pledged support as members to the group.



*James Smith with his family*

## Sharing my story in Parliament

**YOUR  
STORIES**

**James Smith who is living with MND was invited to attend the All-Party Parliamentary Group (APPG) meeting in Parliament to tell his story. Here he gives an account of his experience.**

I was beyond thrilled when I received an invitation to share my story at the All-Party Parliamentary Group (APPG) meeting in Parliament. It was a significant opportunity for me to raise awareness of MND on a national platform and advocate for better support and resources for those living with this condition.

As someone personally affected by MND, I understand the importance of shedding light on the challenges faced by individuals and families dealing with this debilitating disease. Accepting the invitation to speak at the APPG was my way of giving a voice to the MND community and advocating for positive change.

Walking into Parliament, I felt a mixture of nerves and excitement. The thought of speaking in front of MPs and Parliamentarians was both daunting and empowering, but I felt very supported from everyone at the Association and the APPG.

As my turn to speak approached, I drew strength from the knowledge that my words had the power to make a difference.

Sharing my journey of living with MND in front of an attentive audience of MPs was a deeply emotional experience. I spoke from the heart, recounting the challenges and uncertainties, but also the moments of resilience and hope that have defined my journey. The support and empathy I felt from the room filled me with gratitude and reinforced my belief in the power of storytelling to drive positive change.

The MPs listened intently, asking thoughtful questions,

and expressing a genuine interest in understanding the impact MND has on individuals and their loved ones. It was a humbling experience to know that my story was resonating with those in a position to influence policies and drive initiatives that could improve the lives of people living with MND.

As I concluded my speech, I received a round of applause from everybody in the room and felt a sense of accomplishment and fulfilment. I knew that by sharing my story in Parliament, I had hopefully made a meaningful contribution to the ongoing conversation about MND awareness and support around treatments.

Afterwards, I spoke to Andrew Lewer who held a meeting among other captivating MPs, Parliamentarians, and attendees. I received the most amazing feedback and encouragement, and even had MPs wanting selfies and photos with me. I almost felt like a celebrity.

I left the meeting on a massive high, but the day didn't end there. I was lucky enough to have a personal tour and a behind-the-scenes look around the Houses of Parliament, which was amazing and possibly a once in a lifetime experience.

As I made my way home from what was the most amazing but tiring day, I had feelings of renewed hope and determination to continue advocating for a brighter future for all those affected by MND.

Thank you again to everyone involved and thank you for giving me this opportunity. It will be one I will remember.

# Thank you

to all our fundraisers

Share your pictures at  
[www.facebook.com/  
mndassociation](https://www.facebook.com/mndassociation)

If you are sending in photographs to feature on these pages please ensure you have full permission to use the images.



£2,600

**Over the hills:** Emily Robinson, her sister Claire Eason, and their partners completed the Ultra Challenge Chiltern Hills 50K Trek. The family have had two loved ones diagnosed with MND. Their grandmother Dorothy died from MND in 2003, and in 2022 their dad Stephen was diagnosed.



£4,000

**Celebrating Dad:** Ten years ago, Lorna Ford's dad died from MND. To celebrate his life and raise funds for ethical research into MND Lorna, along with her brother Richard, organised a band night in Chesterfield.



**Thank you Sheila:** The North Devon Group would like to thank Sheila Edwards, a wonderful volunteer for over 30 years. Sheila played a massive role in the Group, and over the years has been a chief awareness raiser, meeting co-ordinator, fundraiser, Helpline volunteer, Group contact, event planner, vice chair and most recently Group leader. We all are truly thankful for everything Sheila has done over the years.



£7,000

**Show time:** Variety Express Drama Group put on quite a show at St Francis' Theatre in Letchworth raising £7,000 for the Hertfordshire Branch of the MND Association. The drama group is fundraising in support of Variety Express member Darren Stephenson who is living with MND.



£3,600

**Team Palmer:** Team Palmer completed a 55 mile London to Brighton bike ride, crossing the finish line in Brighton having raised £3,600 to support other families affected by MND.



£27,500

**For Rob:** Rob Steele who is living with MND, and his friend and former professional England rugby player Victor Ubogu organised a 'Rob's Uno Mass Party' at Tonbridge Angels Football Club. Over 600 people joined them to raise funds for the MND Association and My Name's 5 Daddie Foundation.



£14,500

**72 holes in 24:** Paul Gilbert who is living with MND, his sons Max Jayy and Lukas, and friend Jamie Gerrard took part in a '72 holes in a day' golfing challenge to raise funds for the Hertfordshire Branch. Paul was overwhelmed to have raised so much and said: "I'd like to say a big thank you from the bottom of my heart to everyone for their support."

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](https://www.mndassociation.org/fundraising)



£7,580

**Three Peaks for three mates:** Eli Clarkson and her three mates, Dom Trett, George Alton and Michael Waller took on the Three Peaks Challenge, inspired by their cricket club friend James Baldock who is living with MND. They conquered Ben Nevis and Scafell Pike and were making great progress until Hurricane Nigel hit. With 70mph winds, they had to postpone their ascent of Snowdon. When they returned to complete the challenge, family and friends joined them for their final peak, raising £7,580.



£3,000

**Disco Tracey:** When Tracey Hunt's friend died from MND she decided to organise a fundraising disco to honour her friend and raise money for the MND Association. 'The Disco through the Decades' was a huge success, with many coming in fancy dress.



£38,000

**Community spirit:** David Hughes called on 60 of his closest friends from Tandridge Village to walk the Beachy Head Marathon route in support of a neighbour recently diagnosed with MND. The friends completed the challenging route that included over 4,000 feet of climbing.



£1,600

**7 in 7 at 70:** Inspired by our patron Kevin Sinfield CBE's fundraising, Steve Pursglove created his own '7 in 7 at 70' challenge, spurred on by thoughts of his friends Lloyd Edwards and John Ancliffe, who both died from MND. Steve ran 7 miles on 7 consecutive days, culminating on his 70th birthday on 18 December. Steve said: "This experience has given me a sense of purpose, and I'll be looking for volunteering opportunities in my local area to help the Association."



£36,500

**50 strong:** Ben Lighting, who is living with MND, and his wife, Lucinda, organised a team of 50 friends and family to take part in the Guildford 10K run. After the huge success of the run, Ben and Lucinda are already planning their next event - a charity golf day!



£8,600

**Drive for a cure:** Mike Hammond and Robin Baines drove in Robin's Austin Opal 7 vintage car from Ness Point in Suffolk to St David's on the Pembrokeshire Coast in memory of Robin's dad David, and Mike's son Justin, who both had MND. They raised £8,600 for the Norfolk, Norwich and Waveney Branch.



£15,800

**From Mizen to Malin:** Tom Gidman and his friends Elliot Smith, Joe Duffelen and Chris Thomson braved the rain, winds and hills to cycle the length of Ireland. The 925 km journey started at Mizen Head in the south, ending in Malin Head in the north.

## Members' letters

If you have something you would like to share with other members of the MND community, we would love to hear from you. Letters, which must include your full address, can be sent via email to [editor@mndassociation.org](mailto:editor@mndassociation.org) or posted to Your letters, *Thumb Print*, Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ

Please note that letters may be edited. If you are including photographs please ensure you have full permission before sending.

Dear Editor,

**I would like to tell you about why my brother, Ravinder Brar and I are raising awareness of MND. My mother, who is lovingly named Rani (meaning Queen), has always been a resilient individual, but she is unfortunately suffering from MND. Last year, I made a conscious decision to actively raise awareness in both the UK and abroad.**

Coming from a family of doctors, with a father who is tirelessly dedicated to supporting my mother, I felt compelled to share our story with friends and the Wim Hof Community ([www.wimhofmethod.com](http://www.wimhofmethod.com)). My family puts in a great deal of effort to assist my mother, and I am immensely proud of my father and brother for their unwavering support.

My mother successfully managed her own businesses alongside my father, which they built from the ground up. They made significant sacrifices to provide for their children. My mother would wake up early and be the last one to go to bed, ensuring that everyone was taken care of.

In 2005, my mother had the pleasure



Arvinder Brar is pictured second from left during his six-day expedition to Karparc, Poland where he met Wim Hof

of meeting Her Majesty Queen Elizabeth during a visit to our workplace. The excitement on that day, when our 'Queen Mum' was in the presence of the Queen of England, remains a remarkable and cherished memory.

Unfortunately, my mother's health has deteriorated significantly. Witnessing this decline has been heart-wrenching for me and has caused immense grief

for everyone involved. In an effort to support her, I began exploring methods involving cold exposure and came across Wim Hof [Editor's note: a motivational speaker and athlete]. After much practice, I made it a goal to meet him in person and participate in his six-day expedition in Karparc, Poland. This trip not only helped raise awareness for the MND Association but also provided me with the opportunity to share personal stories about MND with over 400 people at the camp. Trekking a mountain in shorts amidst the snow and sitting in cold rivers were exceptional experiences.

In addition to this trip, my brother and other relatives have participated in mud runs and treks at Seven Sisters to help raise funds for the cause. Personally, I will always cherish the Hindi lullaby that my mother used to sing.

'Lalla lalla lori, doodh ki katori, Doodh mein bataasha, Anandh kare tamasha.'

Arvinder Brar



The MND Association is committed to minimising impact on the environment. Our fully recycled paper wrap is 100% sustainable and the most environmentally friendly solution available.

*Thumb Print* is printed on paper sourced and certified by the Forest Stewardship Council (FSC) and is carbon balanced – offset by The World Land Trust – an international conservation Charity committed to buying and protecting environmentally-threatened land throughout the world

## Alyson

People walk on by me, they talk amongst themselves.  
If they paused and looked into my eyes, they'd see I'm still myself.  
In my head, I feel able bodied just like you.  
But my muscles they won't let me – they won't let me move.  
My limbs – I can feel them. I feel from head to toe.  
But they don't understand me, I no longer have control.  
And though my mouth may open, the words just won't come out.  
My voice has been stolen. I cannot scream or shout.  
My eyes – they see clearly as the world passes me by.  
I watch, stuck in my body whilst I wither away inside.  
My heart is still open – my feelings still the same.  
But how can I express them trapped inside this brain?  
Another day, I try to be happy because I'm still here, and I'm still Ally!



Alyson Lewis

*Written by Rosie Hollings who spent nine years as a carer for her late mum Alyson Lewis, from Caerphilly, South Wales*

## Carer

She knows this body like a lover – its hollows, rounded hills,  
an unfamiliar landscape now explored by strangers.  
This body is not mine – skin and bone have aged  
in new formations, weathered in ridge and furrow.  
I am my shadow, watching priestly ceremony, rituals of cleansing,  
each orifice sluiced, anointed, purified.  
My shadow cannot recognise this puppet dance this passive child  
this obedient shadow.



Lynda Turbet

*Lynda Turbet, who is living with MND. From an anthology of published short stories and poems 'Something to Say'.*

## 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 MND Connect helpline offers advice, practical and emotional support and signposting to other organisations. Please note our revised opening times:

**Monday to Friday 10am to 4pm**

**mndconnect**

**0808 802 6262**

[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

## Membership

To receive a regular copy of *Thumb Print*, call 01604 611860 or email [membership@mndassociation.org](mailto:membership@mndassociation.org)

If you would prefer to receive your copy of *Thumb Print* under plain cover please let our membership team know.



## MND Matters

*MND Matters* is the Association's podcast series, sharing stories, advice and information from and with members of the MND community and beyond.

Listen to the latest episodes on our website at [www.mndassociation.org/mndmatters](http://www.mndassociation.org/mndmatters) or search *MND Matters* in your chosen podcast provider.

### Episode 31: Tanya Curry, one year on

A special anniversary episode where our Chief Executive Tanya Curry speaks with Tanya Arnold, sports journalist and patron of our West Yorkshire Branch. Tanya discusses her tenure so far, her passion for supporting people affected by MND, and her ambitions for the Association in 2024 and beyond.

### Episode 30: *The Love Inside*

In this episode, host Helen chats to the MND Association's Director of External Affairs Chris James to find out more about our latest awareness campaign, the reasons behind exploring TV advertising for the first time in years and what the Association hopes to achieve from *The Love Inside*.

### Episode 29: Cultural challenges with MND

In this thought-provoking episode, Yvonne Johnson, living with MND, and author Liv Little, whose dad died from MND in 2022, talk about some of the cultural challenges around navigating the disease.



Coming Soon

## The MND Association Summer Raffle

As a *Thumb Print* reader, you're getting an exclusive sneak peek of our Summer Raffle! The countdown is on, so get ready to play as soon as it opens.

Thanks to wonderful supporters like you, our last Summer Raffle raised over **£96,000** to provide 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!

1st prize:  
**£5,000**

2nd prize:  
**£1,000**

3rd prize:  
**£500**

20 x  
Runner-Up  
prizes: **£25**

**RAFFLE OPENS FOR ENTRIES ON 2 MAY 2024**

Once the raffle is open, you can enter online by visiting [mnda.raffleentry.org.uk](https://mnda.raffleentry.org.uk) or by calling **0330 002 0342**

**Closing date: 18 July 2024    Draw date: 30 July 2024**

**mnda**  
motor neurone disease  
association

Scan here after 2 May 2024 ▶



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](mailto:raffle@mndassociation.org) once the raffle is open.

**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 will be made available once the raffle opens at [mnda.raffleentry.org.uk](https://mnda.raffleentry.org.uk) for full terms and conditions including information on prize allocation, proceeds and chances of winning.

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