motor neurone disease association
Membership

THUMBPRINT

NEWS FROM THE MND ASSOCIATION COMMUNITY
AUTUMN 2024

Meet the MND researchers of tomorrow

EnCouRage UK 2024

Welcome
from our Chief Executive

By the time you read this, we will have launched the 23rd and newest MND care and research network in England, Wales and Northern Ireland.

The South West London and Surrey Network will link the existing MND clinic at St George's Hospital in Tooting, South London with eight community hospitals, hospices and multidisciplinary teams in the area, bringing care for people with MND closer to home. It's taken a huge collaboration between people with MND, our expert teams and the NHS trust to get us to this point. Thanks to all their efforts, and a significant investment from the Association, there is now a four year commitment to provide dedicated MND care co-ordination. This will make it easier for people with MND in the area to access the right level of care and support from specialist healthcare professionals.

Meanwhile our investment in the future of MND research continues. The wonderful photo on the front of this issue of Thumb Print was taken at this year's EnCouRage UK event. It features some of the faces of the future of MND research, our Early Career Researchers (ECRs – hence the capital letters in EnCouRage). The two-day event provided opportunities for the researchers to network, learn new skills and share their work. It was truly inspiring to see their dedication and commitment, and several of them told me they were equally inspired by talking to the people with and affected by MND who shared their own stories at the event.

If you'd like to hear first-hand about the global research efforts to understand more about MND and the search for treatments, you can sign up to attend our 35th International Symposium on ALS/MND. This year's Symposium is taking place in Montreal, Canada, in December with many of the presentations and sessions also available online. See page 12.

Of course, our commitment as an Association to funding care and research can only continue because of the incredible efforts of our supporters – you're all amazing! I must give a special mention to Manette Baillie who, at 102, chose to fundraise for the Association by undertaking a parachute jump – what a woman! A big well done and thank you to the 4,461 people who signed up to our August Facebook challenge – Run 60 Miles. I know some of you pulled on your trainers to run at 5am to avoid the heat, rain and wind which the British weather has thrown at us this summer. We are grateful to you all. Slightly less weather dependent is our 5000 Squats in November challenge which you could do in the comfort of your own home. Follow us on Facebook to find out more.

And finally, please join me in welcoming our four new trustees, voted onto our Board by you, our members. You can meet them on page 27. Trustees have a vital role to play in ensuring we, as an Association, are delivering for our community. While it's a voluntary role, it's one that takes a lot of energy and dedication so we are very grateful to all those who choose to give us their time in this way.

Tanya Curry, *Chief Executive*

IN THIS ISSUE:

On the cover: Early career MND researchers attending the recent MND EnCouRage UK 2024 event

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motor neurone disease association

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***Thumb Print* is available to read online at www.mndassociation.org/thumbprint**

Inspiring the next generation

> The opportunity to present in front of people living with MND was really fantastic, being able to communicate what's going on in the labs so they have a better understanding, and also getting some perspective on our work back from people affected by MND.
>
> Katie Bowden, PhD student

Talented early career researchers (ECRs), people affected by motor neurone disease (MND) and leading MND researchers gathered at EnCouRage UK 2024, organised by the MND Association.

The event is aimed at inspiring young scientists to collaborate, connect and focus their careers on understanding MND to secure the next generation of MND research leaders.

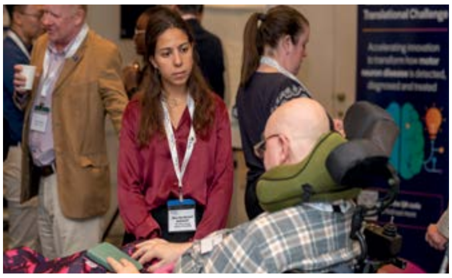
More than 20 ECRs attended the event, joined on the second day by a group of people affected by MND. With a jam-packed programme, the event kicked off with a compelling presentation from Simon Hall, a former BBC correspondent, author and journalist, who now lectures at Cambridge University. He grabbed everyone's attention with a workshop designed to help ECRs develop compelling and powerful presentations.

Simon Hall who provided an interactive session for ECRs

'Lightning talk' sessions gave individual ECRs the chance to showcase their research in a succinct and easily understandable way. Informal, interactive sessions with communications professionals also gave them hints and tips for better explaining scientific research to lay communities.

ECRs engaged with the MND community, to discuss the importance of their research and hear what it means to people living with MND. Katie Bowden, PhD student from SiTraN (Sheffield Institute for Translational Neuroscience) said: "The opportunity to present in front of people living with MND was really fantastic, being able to communicate what's going on in the labs so they have a better understanding, and also getting some perspective on our work back from people affected by MND."

ECRs and people affected by MND were able to network with world-leading researchers, with a focus on the vital need to include patients in early drug discovery. Professor Ammar Al Chalabi, Professor of Neurology and Co-director of the UK MND Research Institute, also led a lively and thought-provoking discussion about clinical trials, looking at different perspectives and highlighting the importance of involving people affected by MND in trial discussions at the early stages.



Read more about MND EnCouRage UK 2024 in our MND research blog https://mndresearch.blog/2024/07/18/mnd-encourage-uk-supporting-the-future-leaders-of-mnd-research/

# of researchers

I thoroughly enjoyed my time at MND EnCouRage UK. I've met so many bright-minded, dedicated peers and experts. I've learned so much about science communication! And most importantly, had the opportunity to connect with people affected by MND.

Laura Odemwingie, PhD student at King's College London

It's not just important for early career researchers to meet us and to understand that there's people behind the disease, but also for us to meet them to understand the amazing work they're doing. The highlight has been listening to all the research. It's been such a positive experience.

Anna, who is living with MND

Events like this are really important. It's critical we learn to communicate effectively and it's the support that the wider public give us which allows us to do what we do. I am funded by the MND Association and, without that support, I wouldn't be doing what I'm doing now.

Dr Ben Clarke, ECR at Francis Crick Institute

I had a wonderful time at MND EnCouRage UK, connecting with people affected by MND and dedicated scientists. Science is fun, our work matters, and public engagement is vital. I'm inspired by everyone's stories and wish I'd joined this event sooner.

Dr Yiran Wang, MND Association fellowship holder and ECR

The work early career researchers do is probably one of the most important aspects of MND research. Ultimately, we hope as an Association that by investing in these talented individuals, we are investing in a cure for MND – one of the people in that room could go on to find the key we all desperately want.

Mandy Spencer, Research Engagement Officer at the MND Association

The work that the MND Association does in funding our research and supporting people who are living with MND is so critical for me as a researcher. MND EnCouRage UK is energetic, hopeful and collaborative!

Dr Rebecca Saleeb, Research Fellow at the University of Edinburgh

10 years on
Ice Bucket Challenge

It's ten years since the Ice Bucket Challenge, the fundraising phenomenon which started on social media and took the world by storm, marking a turning point in the Association's history.

Having started in the USA, the Ice Bucket Challenge soon began making waves around the world throughout the summer of 2014. In the UK, the Ice Bucket Challenge started to gain momentum over the August Bank Holiday weekend with money flooding into the Association's JustGiving fundraising page which was set up by volunteers Paula and Robert Maguire. In total, an incredible £7.25 million was raised.

Headlines across the world

For the very first time, MND was being talked about on primetime TV, dominating the news agenda for days. Between 11 August and 8 September, the MND Association and MND were mentioned in 3,120 news articles and on major news channels at home and abroad.

Former S Club 7 star, Jon Lee, whose father was living with MND at the time, perhaps put it best when he said: "It's impossible to try and prepare friends and family for the reality of MND but then the Ice Bucket Challenge was born.

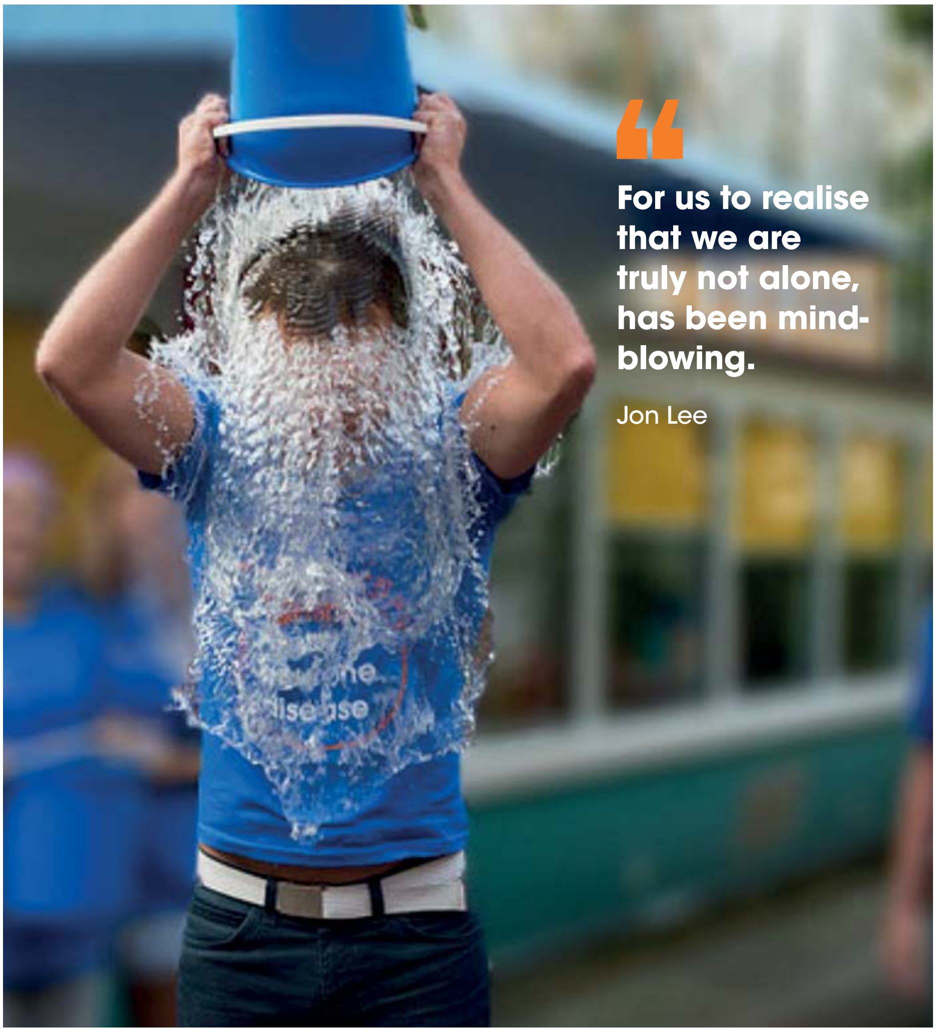
"Suddenly this disease was famous. It gave us strength and something this disease has never had to offer – hope. To see the world come together and shine a spotlight on MND for the first time, and for us to realise that we are truly not alone, has been mind-blowing."

A springboard to progress

MND Association members played a key role in determining where the money raised should be spent. As a result, the Association invested £4.9 million in research studies which aim to understand the genetic basis of MND. Among them is Project MinE, the largest genetic research project to date and the AMBRoSIA study, which is one of the world's most comprehensive MND sample collections.

In the years since, Project MinE has collected DNA from more than 11,000 people across the world. In 2022, it was announced that 15 new genetic profiles which showed an increased risk for developing MND have been found through the study. The data has also been used in several research studies to help identify possible subgroups of the disease and look for new potential treatments.

Through the AMBRoSIA study, three centres across the UK have collected samples from 525 people with MND, along with 398 healthy people. The samples have been made available to the research community to study biomarkers of MND. AMBRoSIA led to the confirmation of a particular biomarker of MND, called neurofilament light chain which holds the neurones together and is released by the cells as they die. Due to this research, neurofilament light chain is now being used in clinical trials of potential treatments for MND to measure disease progression and assess whether the treatment works.



> **For us to realise that we are truly not alone, has been mind-blowing.**
>
> Jon Lee

The Ice Bucket Challenge raised £7.25 million for the MND Association

Launch of new support

A further £1.48 million was invested in boosting the Association's MND care centres and networks, ensuring people living with MND were able to access high quality multidisciplinary care. The money was targeted into opening two Care Centres in Norwich and Norfolk, and the North Midlands, as well as the recruitment of four specialist MND nurses, and two Care Co-ordinators.

We also developed new resources for children and young people whose lives have been affected by MND and set up the Welfare Benefits Service. A further £750,000 was spent on campaigns which helped to raise awareness of MND, while £120,000 was allocated to recruiting and training new volunteers.

Care and Research Network

launches in South West London and Surrey

Left to right: Kate Slemeck, St George's Hospital Managing Director, Kuai Peng a carer, Pablo Garcia-Reitboeck, Consultant Neurologist – MND Clinical Trials at St George's, Camilla Blain, Consultant Neurologist and Clinical Director of Neurosciences, David Setters who is living with MND, Clare Galtrey, Consultant Neurologist at St George's MND clinic, Sally Hughes, Director of Services and Partnerships at the Association, Niran Nirmalananthan, Consultant Neurologist and Clinical Director of Neurology for NHSE – Developing South West London and Surrey Neuroscience Network

The Association has made a four-year funding pledge to an MND Care and Research Network serving South West London and Surrey, in partnership with the NHS.

The joint venture will build on the success of St George's specialist MND clinic, based at St George's Hospital in Tooting which has been running since 2017.

The launch of the Network will mean improved support and co-ordination of services for approximately 180 people with motor neurone disease.

It brings the number of MND Association Care Centres and Research Networks in England, Wales and Northern Ireland to 23 representing an annual commitment by the MND Association of £1.6 million.

Kuai Peng is a carer for her husband KT, who was diagnosed in 2015. She said: "Co-ordination of care for people with this disease is vital, as is communication and continuity between different clinicians and departments.

"Spending less time on health appointments, factoring in the difficulty in travel that is required to attend them, means you have much more time for other things.

"Caring for someone with MND is not always easy, so to have this support is brilliant and I hope it will benefit many families who use the service in the future."

The move will see an MND Care Co-ordinator, based at St George's Hospital, become the single point of contact for people with MND.

The complexities of the disease mean visits to numerous healthcare professionals at any one time, which can be overwhelming and exhausting. The Co-ordinator will link in with eight community MND multidisciplinary teams, eight hospices and eight district general hospitals in the area.

> **Caring for someone with MND is not always easy, so to have this support is brilliant and I hope it will benefit many families who use the service in the future.**

Claire Bickley, Head of Regional Services and Partnerships for the South at the Association said: "We are delighted to launch our latest care network, the first of its kind in six years, in partnership with the amazing team at St George's.

"With the geographical catchment area of the clinic increasing in the last two years, it is vital every person with MND in the region receives the care they need and deserve.

Tofersen update

Plans for a campaign to raise awareness of what we feel is an unfair decision by NICE (National Institute for Clinical Excellence) regarding the drug tofersen are underway.

Tofersen has been shown in clinical trials to slow the progression of symptoms in people living with MND (motor neurone disease) who have alterations in the SOD1 gene.

This is approximately 2% of the MND population, thought to be between 60-100 people in the UK. Leading experts have called for the drug to be appraised by NICE through its Highly Specialised Technology (HST) route.

However, NICE confirmed it would assess the drug through the Single Technology Appraisal (STA) route instead.

The MND Association believes this decision is wrong and will prevent tofersen from being made available on the NHS.

We are pleased Biogen's early access programme for tofersen currently remains open to people with SOD1, but are preparing to go further in our campaigning efforts against this verdict.

MND Guarantee

85 new MPs sign up

The 2024 General Election was a key moment for the MND Association to set out its expectations of how a new government could improve care and support for people affected by MND.

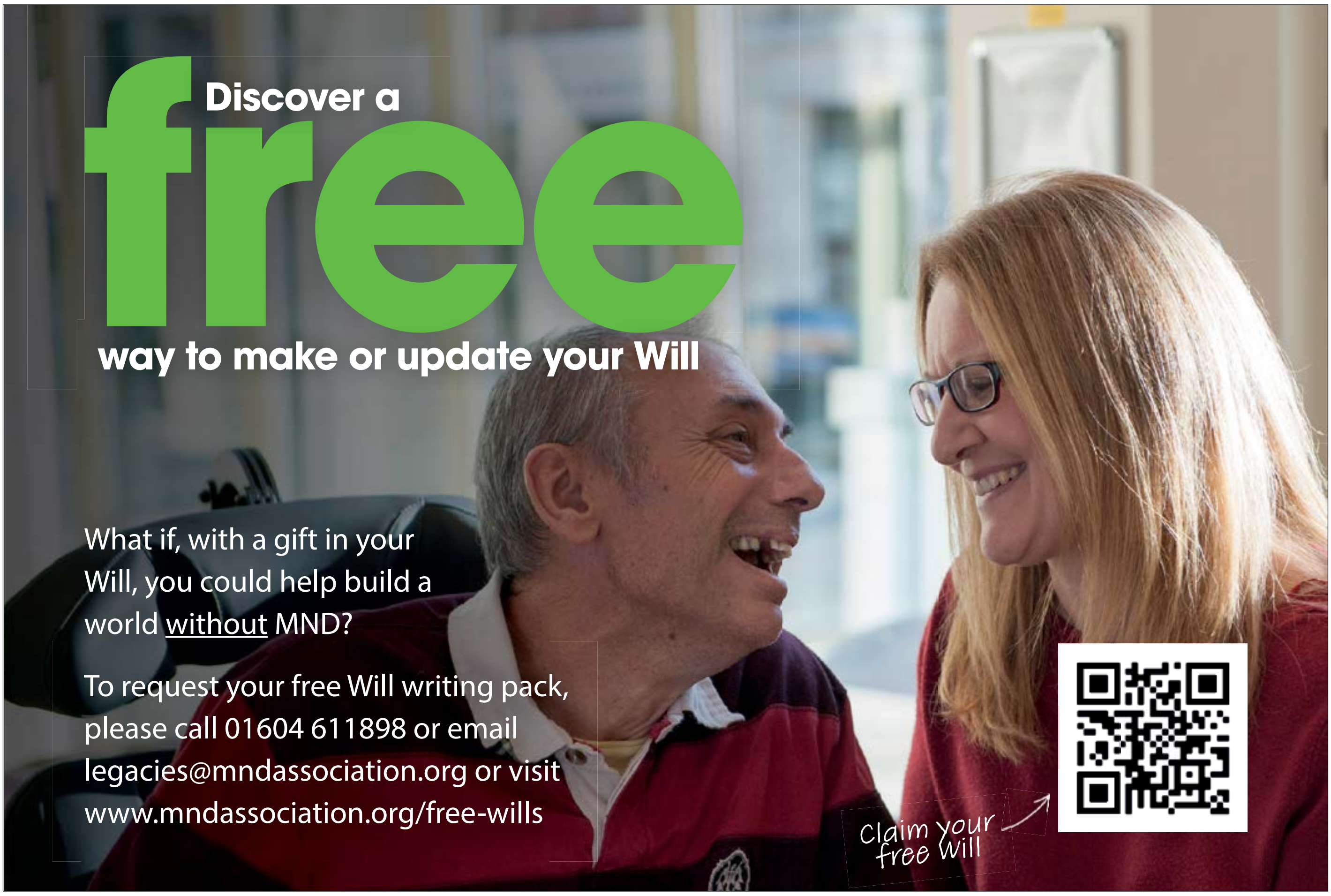
The Association launched the MND Guarantee campaign in May, just before the Prime Minister called the election for July 4. With the election announced, the focus was on working with the MND community to ask parliamentary candidates to commit to supporting people living with and affected by MND if elected.

Association supporters and campaigns volunteers wrote to parliamentary candidates in their areas, asking them to sign our *MND Guarantee*. This support was crucial. Volunteers across the country reached out to candidates, advocating for the campaign and ensuring the *MND Guarantee* was widely recognised.

This collective effort resulted in more than 400 candidates from around 45% of constituencies signing the *MND Guarantee*. 85 of those candidates were elected as MPs and the Association teams are now working with those individuals to build relationships.

The Association's Director of Engagement, Richard Evans said: "Thank you to everyone who took the time to contact their parliamentary candidates to discuss the *MND Guarantee*. The hard work and dedication of our supporters means more than 10% of the UK's MPs have made a commitment to work on issues that affect the MND community. That gives us a great springboard for influencing decision-makers."

If you'd like to meet your new MP to discuss the issues faced by people with MND, email **campaigns@mndassociation.org** and we will send you a template email to support your ask which also details the actions we want the government to take. Your involvement can make a significant difference in ensuring the voices of those affected by MND continue to be heard in the new parliament.



What if, with a gift in your Will, you could help build a world <u>without</u> MND?

To request your free Will writing pack, please call 01604 611898 or email legacies@mndassociation.org or visit www.mndassociation.org/free-wills

Coronation Street
Reflections on the MND storyline

PROMISE 4
WE WON'T REST UNTIL
YOU ARE HEARD

18 months ago, ITV's *Coronation Street* viewers noticed character Paul Foreman dropping glasses and throwing wayward darts.

Some, rightly, guessed it was the first symptoms of MND and gradually Paul began encountering many of the physical and emotional challenges faced by the 5,000 people in the UK living with MND right now. The inevitable conclusion to the storyline was Paul's death in an incredibly moving episode aired early in September.

News of Paul's MND storyline was greeted, within the MND community, with interest and some trepidation – would it offer an in-depth insight into the impact of MND, or fall short? Thanks to the diligence of the scriptwriters and comprehensive guidance given by the Association, the storyline has been received positively.

Corrie fan Margaret Waller, who has MND, said: "Because Paul is a young and likeable character, I felt that, if it was handled carefully, it would bring home to viewers the terrible nature of MND and its impact on the lives of everyone concerned.

Still from the last episode of the MND storyline

"I think the acting has been excellent in showing how abilities disappear one by one and what a challenge it is to cope with each loss - mobility, dexterity, speech, eating, and the emotional toll it takes on everyone concerned."

Being a similar age to Paul and receiving a diagnosis around the same time, mum of three Anna Barrow noted similarities with her story. Speaking to I newspaper in July, Anna said: "When the storyline started to pick up momentum and I would meet new people, I found I had to explain myself less. Having to always explain what it is can be exhausting. Now people know what I mean when I say I have MND. They're like 'Oh, like the guy off *Coronation Street*?' That's so helpful."

The storyline on the cobbles gave the MND Association a unique opportunity to tell its own story. In January, we launched The *Love Inside* campaign featuring three people living with MND. The powerful adverts, our first to be aired on television in ten years, took *Coronation Street* viewers and the wider public beyond the fictional storyline and into the reality of MND. They were backed up by advertising on billboards and social media.

On days our TV ads aired, we saw a 145% increase in sign-ups for regular giving and an 82% increase in cash donations. As of July, approximately 13% of the UK adult population had seen our TV adverts and more than 7,600 new supporters had signed up.

As the storyline drew to a close, the campaign was stepped up with adverts airing during daytime programmes including *This Morning* and *Loose Women*.

The *Love Inside* campaign and Corrie storyline have both secured national awards and nominations. Actor Peter Ash scooped a prestigious National Television Award and the storyline saw off stiff competition to win the RadioTimes.com Soap Award for Best Storyline. The *Love Inside* was shortlisted twice in the Third Sector Awards.

A proud Peter Ash backstage after receiving his NTA award in September

Richard Evans, Director of Engagement at the MND Association, said: "The *Coronation Street* storyline has now ended and the Street's residents will move on. But we can't - and mustn't, for the sake of everyone in our community and the six people who are diagnosed with MND every single day.

"We will now be working not just to build on the awareness but to use it to benefit people with MND by engaging with those people who now understand more than ever what a brutal disease it is."

Manchester and District Branch
40 years old and still going strong

When the Manchester and District Branch of the MND Association was set-up in 1984, there were no emails or computers, and volunteers had to communicate via letters and phone calls.

Fast forward 40 years and volunteers are now on mobiles, emails, WhatsApp, texts and of course, still very much face-to-face. Through their hard work and dedication, the Branch has grown considerably over the years and it has been responsible for many innovations that have since gone on to make a huge difference to people affected by MND nationally.

> **What keeps us going is the people living with MND who come to us scared and unsure of the future. I'm sure our help makes life easier. We will carry on until one day we have a huge party celebrating a cure and end of MND.**

Birthday celebrations at the Manchester and District Branch

The Stockport Support Group initiated the *Understanding My Needs* leaflet and after a year's trial the leaflet was rolled out across England, Wales and Northern Ireland. The Group also piloted the MND Association's Benefits Advice Service and it was the first branch to have Association visitors attend clinics at the Salford Royal MND clinic.

To mark 40 years, the Manchester and District Branch held an event at Sale Football Club where Chair Phil Bennett gave a brief history and Sue McCormick shared how the Branch was first set up and how it has developed into what it is today.

Phil said: "What keeps us going is the people living with MND who come to us scared and unsure of the future. I'm sure our help makes life easier. We will carry on until one day we have a huge party celebrating a cure and end of MND."

Sally Light awarded OBE

The Association's former Chief Executive, Sally Light has been awarded an OBE in the King's Birthday Honours for her services to people with MND.

Under Sally's leadership the Association's annual income grew from £13 million to £30 million, enabling more investment in research and supporting care. The charity also invested in campaigning, leading to the introduction of the NICE guideline, changes to the welfare benefit rules affecting people with a terminal illness and a government commitment to invest £50 million in targeted MND research.

Sally's ten year tenure also included the viral Ice Bucket Challenge in 2014 (see page 6), the rapid development of the Project MinE genetic research collaboration and the creation of the development of the Ambrosia biobank in response to demand from the research community as well as the delivery of an extensive library of award-winning literature, guides and resources for people with and affected by MND, and the professionals who support them.

In 2022, just before leaving the Association, Sally was presented with the 2022 Humanitarian Award by the International Alliance of ALS / MND Associations for her leadership in raising awareness and action around MND.

Sally Light, former Chief Executive of the Association

Sally is due to receive her honour from a member of the Royal family later this year.

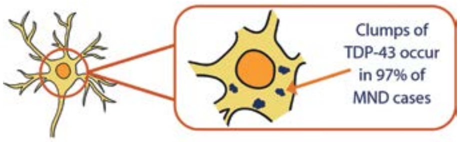
TDP-43 clumps
Can they predict MND progression?

Dr Rebecca Saleeb, who is funded by the MND Association

> **My expertise is actually microscopes of all things, but I've always wanted my research to be impactful for the general community, and there is nothing to me more impactful than working on MND.**
>
> Dr Rebecca Saleeb

The onset of symptoms and the progression of MND can vary dramatically from one person to another, making it difficult for clinicians to diagnose and give accurate information about how the disease might develop.

Researchers are working hard to identify new methods to diagnose and monitor MND, with a particular focus on finding biomarkers. Biomarkers are unique biological signals of a disease in the body. For example, a simple blood test can be used to diagnose and monitor diabetes by measuring levels of blood glucose levels. The aim is to identify and develop similar tests for MND.



One MND Association-funded researcher who is searching for MND biomarkers is Lady Edith Wolfson Non-Clinical Fellow Dr Rebecca Saleeb from the University of Edinburgh. Dr Saleeb said: "I'm working to try and develop ways to diagnose MND in the early stages so that we can regain precious time we are losing during the diagnosis process."

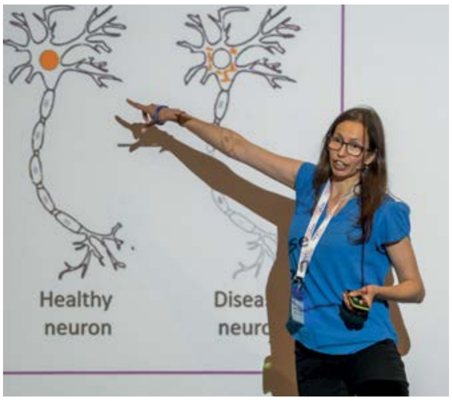
Dr Saleeb's research focuses on a particular protein, called TDP-43. In around 97% of all MND cases, TDP-43 clumps together. This damages motor neurones and causes them to die. One theory which could help explain why there is a difference between symptoms and severity in people with MND, is that TDP-43 clumps together. This damages motor neurones and causes them to die.

However, these clumps are extremely small, about 10,000 times smaller than the width of a human hair. To be able to look at these clumps in detail, Dr Saleeb is using a custom designed, state-of-the-art microscope. She said: "My expertise is actually microscopes of all things, but I've always wanted my research to be impactful for the general community, and there is nothing to me more impactful than working on MND."

Initially, Dr Saleeb will use post-mortem tissue to characterise the differences between TDP-43 clumps and identify different clump types. She will then see if the type of clump relates to how the disease develops. If this is the case, then TDP-43 clumps could have the potential to be used to more accurately predict a person's progression.

To make this into a test which could be used in the clinic, a different approach to collecting samples is needed. Samples from the brain or spinal cord cannot be taken from people while they are alive. Instead, cerebrospinal fluid, which is often taken as part of the diagnostic process, could be used. Once the identification of TDP-43 clumps has been perfected in post-mortem tissue, Dr Saleeb will use cerebrospinal fluid samples from people with MND, to see if the clumps can be analysed in the same way.

This research is currently in its very early stages. We will share Dr Saleeb's research as it progresses.



Are you ready for a new challenge?

For Mary Phillips, 2024 is the year she pushed herself to the limit by completing the 100km Lake District Ultra Challenge to raise money for the MND Association.

It was an experience Mary will never forget, as she explains: "It was incredible, even when the rain blew in at 4am and I had to dig deeper than I ever have before. Walking across the finish line was met with relief and exhilaration - quickly followed by a delicious bacon butty! I met the most wonderful and inspiring people, all with their own reasons to complete the challenge."

Mary took part in one of a series of 18 treks across the UK. The Ultra Challenge Series run by Action Challenge offers a range of challenging treks, covering coastal paths, lakesides and hills. People taking part can choose to walk or run 10km, 25km, 50km or 100km, either on their own or as part of a team.

The MND Association is an official partner of Action Challenge, so there's a 50% discount on registration fees if you choose the charity sponsorship option on any of the 2025 challenges. From winter walks in London, to coastal treks in the South West and a new, exciting trek for 2025 in the stunning Gower Peninsula, there is a challenge for everyone. Whichever challenge you choose, you'll receive warm hospitality, marquee rest stops, free food and drink, with full support through day and night to get you to the finish line.

To find out more about, visit www.mndassociation.org/ultra.

Mary Phillips

35th International Symposium on ALS/MND

In December the beautiful city of Montreal, Canada will host the MND Association's 35th International Symposium on ALS/MND.

Researchers, and health and social care professionals from more than 30 countries are expected to attend to share knowledge, exchange ideas and create new collaborations in the collective fight against MND.

This year a record-breaking number of research projects will be showcased through talks and poster presentations at the three day event running from 6 to 8 December. These projects highlight the breadth of MND research underway globally. The programme also includes presentations from 20 international leaders in MND research.

Dr Sebastian Lewandowski, from the Karolinska Institute in Sweden, will share his research exploring how the brain's supply of oxygen and nutrients – essential in keeping neurones healthy – may be affected in people with MND. Understanding how reduced blood flow and transfer of nutrients might contribute to MND, could allow for potential new treatments to be developed.

The programme also includes a talk from Professor Douglas McKim, from the Ottawa Hospital in Canada, who will discuss the benefits of non-invasive ventilation techniques in MND. His talk will delve into the current challenges and potential improvements.

Registration for in person and online attendance is now open, with virtual registrations available from 14 September. Please visit: https://symposium.mndassociation.org/ to find out more.

The Big MND BBQ
over 900 attend

A contestant on ITV's *Deal or No Deal* was inspired to fundraise for the MND Association after meeting fellow contestant Brad Wale, who is living with MND.

Once filming ended, Karen Sivewright contacted the MND Association about her idea to hold a Big MND BBQ to bring the community together to raise both awareness and money. After a year of planning, the barbecue was held in June at Macclesfield Rugby Club with more than 900 guests.

ITV's *Coronation Street* stars Sally Dynevor, Peter Ash and Daniel Brocklebank attended and were a big hit with the crowd. Dan's bucket collection alone raised over £500 with the enticement of the offer of a selfie with the stars. Karen also secured a video message from MND Association patron Kevin Sinfield CBE that was played during the event.

Left to right: Sally Dynevor, Daniel Brocklebank, Karen Sivewright, Peter Ash, Richard Shackelford and Cllr Sandy Livingstone (Mayor of Macclesfield)

Dave Sawyer Big MND BBQ Committee member and BBQ aficionado!

More than 400 members of the North West's Rock Choir joined the festivities and at one stage, TV stars Sally and Peter joined the choir to sing along. Volunteers from Manchester and Cheshire MND branches supported the event and talked to guests about the vital support local branches provide. And of course there was the Big MND BBQ with a constant stream of tasty food to feed the crowd.

The event raised almost £8,500 and Karen is hopeful it will turn into a yearly get together. Karen said: "The Big MND BBQ is a chance to bring the community together to raise awareness of MND and raise funds for the MND Association.

"With the possibility of the fundraising initiative being nationalised, we could be at the start of something incredible. The Big MND BBQ idea might be similar to planting an acorn, with everyone's support making the difference in how big the oak tree grows."

AI gives singer back his voice
Technology helps musicians

Musician and singer Stuart Watret is using AI to recreate his singing voice, enabling him to continue with his passion for making music.

Stuart, who is living with MND, is one half of the band Harvey, with long-time friend Carl Holden. The friends started making music together over 30 years ago. Now living in different parts of the UK – Carl in London, Stuart in the Isle of Man – they use email and WhatsApp to share compositions.

> **The first time I heard the AI version of my singing, I couldn't stop smiling. It was incredible and opened up so many possibilities.**


Harvey, with band members Stuart Watret who is living with MND, pictured right, with fellow musician Carl Holden

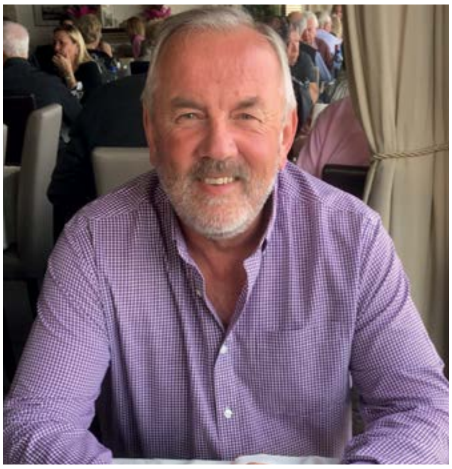
When Stuart's MND meant he lost the ability to sing and play instruments, he began focusing on the production and mixing, pitching in melodies and ideas while Carl played the instruments. One of their latest songs, *Lanterns*, Stuart began experimenting with AI software. Using old recordings of his vocals, the band can take a vocal track from Carl, process it through the AI software and then recreate it to sound like Stuart. AI has given Stuart his voice back and a chance to continue making music in a way that simply wouldn't have been possible without it.

Stuart said: "I always loved music and was singing from as long as I remember. As the MND progressed to the point where my guitar playing suffered we still didn't have a diagnosis. That finally came after years of symptoms. Never did I think my speech would have been affected. If I had, I would have sang and recorded all our old songs knowing I could use them later.

"The first time I heard the AI version of my singing, I couldn't stop smiling. It was incredible and opened up so many possibilities. Because of my MND, Carl now has to play almost everything and that is a huge burden on his shoulders. But he does an excellent job and makes it possible for us to continue to make music."

Carl said: "Stuart was always the lead singer and to give him the ability to 'sing' a brand new track was fantastic. It's given a new lease of life to a singer who could no longer sing. We're both in our 50s, live 350 miles apart and one of us has MND, so we're not looking to build a career. We just want to continue our passion and love of making music."

Visit harveyband.wordpress.com to hear their music.



Gil's song raising funds
for Cambridgeshire Branch

Gil Boyd is a singer-songwriter based in Cambridgeshire and co-host of the Association's support group for veterans living with MND.

Gil, who was diagnosed with MND in November 2022, has written a song about how the disease has affected his life.

His song is raising money for the Cambridgeshire Branch, supporting people living locally with MND. Gil said: "I'm overwhelmed by everyone's generosity in raising funds for Cambridgeshire Branch, who've been so helpful to me on my journey with the disease."

To listen to Gil's song visit www.youtube.com/watch?v=R5xGuCxjH8w

Researchers at Newcastle University lead the way

Left to right: Professor Mark Baker, Professor Andrew Blamire, Dr Fiona LeBeau, Dr Nick Cole

A unique insight into the latest MND research and the importance of gifts in Wills were showcased at a legacy event in Newcastle in July.

Held at the home of the Rugby Union team, Newcastle Falcons, the event, hosted by the MND Association, gave supporters the chance to learn more about research, care and the other services available to people living with MND in the north east.

With one third of the Association's income coming from the generous gifts people leave in their Wills, there was also an opportunity to learn more about how even a small gift can have a huge impact in the fight against MND.

Researchers at Newcastle University are leading the way in MND research and they're seeking answers to important questions around diagnosis and how a faulty protein affects motor neurones.

Can a new scan help diagnose MND?

On average, a diagnosis of MND can take between one and two years. There is no test, and diagnosis involves ruling out other diseases first. Professor Andrew Blamire and his team have developed a new scan which takes images of multiple muscles to look at the structures which control muscle movement. The researchers are now testing how useful this scan is in diagnosing MND, and then plan to run a trial to gain the evidence needed to potentially introduce the scan routinely in the clinic.

> **"It was wonderful hearing from researchers who have dedicated their professional lives to unlocking the mysteries of MND and helping find effective treatments, and one day a cure. Their passion and dedication are remarkable and so inspiring.**

Paying tribute to the contribution those living with the disease make to research, Professor Blamire said: "The involvement of people with MND in my research is critical in the development of this scan and moving it towards routine use."

Why does TDP-43 become faulty?

Dr Fiona LeBeau and Professor Mark Baker both focus on a particular protein, called TDP-43, which is faulty in 97% of all people with MND. Dr LeBeau focuses on understanding more about why TDP-43 becomes faulty and how it is involved in the death of motor neurones.

The findings from this research will help to identify new potential treatments, which Professor Baker can then test on his new model of MND. This new model more closely reflects how MND progresses in people and aims to uncover the most promising treatments. Professor Baker's research is funded by a collaborative funding partnership between the MND Association, My Name'5 Doddie Foundation and LifeArc.

This collaborative environment at Newcastle is just one example of how working together allows researchers to hunt for effective treatments faster. One delegate who attended the event Andrew said: "It was wonderful hearing from researchers who have dedicated their professional lives to unlocking the mysteries of MND and helping find effective treatments, and one day a cure. Their passion and dedication are remarkable and so inspiring."

If you would like to find out more about how you could leave a lasting legacy or our Free Will service, please go to www.mndassociation.org/get-involved/fundraising/leave-a-gift-in-your-will. You can find out more about the research we fund on our website: www.mndassociation.org/research/our-research/research-we-fund

Understanding your needs

My MND, My Needs research outcome

More support to stay independent and help to manage the costs associated with MND are among the key findings from the Association's most comprehensive research to date into the needs of people living with MND.

Findings from the research, called *My MND, My Needs*, show that although support is available through the Association and other support systems, gaps in provision mean certain needs are not being met. Some people affected by the disease are unaware of where to turn to access the support available to them, leading to feelings of isolation.

Sally Hughes, Director of Services and Partnerships said: "This research has provided invaluable insights into the evolving needs of our community. While we're proud of our existing services, such as financial support grants and benefits advice, we recognise the need for further improvement. Your honest feedback will help us enhance our support and advocate for greater awareness and accessibility."

The insights gained from My MND, My Needs are shaping our Association's strategic focus, with five key themes emerging:

The need for autonomy, independence and self-expression

People who took part in the survey said they are struggling with things like keeping on top of tasks around the home, doing things they enjoy and maintaining personal hygiene.

Demand for more financial support

A third of respondents did not feel confident about what they are entitled to. 91% of those taking part said they wanted more support.

A focus on isolation and loneliness

The research highlighted that people with MND living with other adults and children seemed to be experiencing higher rates of loneliness.

Younger people and those living with children have more unmet needs

The report reveals that younger people with children, or other family members to take care of, are facing unique challenges. Making lifestyle changes in line with MND symptoms, often meant making difficult decisions within families.

Making peace with a MND diagnosis enabled some to find more day-to-day joy

Acceptance of the diagnosis and peace with the future were vital, but often unmet needs. Many people who had reached a level of acceptance reported better coping mechanisms and more day-to-day joy despite advanced symptoms. Younger interview respondents and those struggling financially were less likely to have accepted their diagnosis, indicating a need for more tailored support in these areas.

Over the next few weeks, we'll delve deeper into each theme on our social media channels and website.

If you are living with MND or caring for someone who has the disease, we are here to support you. Our MND Connect helpline can give you information and support on all aspects of MND and put you in touch with other relevant organisations which can help further. Call 0808 802 6262 or email mndconnect@mndassociation.org

Corrie star's roll and raise challenge

ITV's *Coronation Street* actor Natalie Amber completed a 41 mile journey from the Bolton Arena to the Blackpool Tower, which was lit up in the MND Association colours of orange and blue.

Natalie, who uses a wheelchair, organised the Roll and Raise Challenge to raise money for MND charities. Everyone was welcome to join Natalie on her journey as long as they were on wheels. People on bikes, wheelchairs, scooters and roller skates braved the bad weather and joined Natalie on her epic challenge.

Supporters will recognise Natalie, who recently played the part of Shelly in *Coronation Street*, working with actor Peter Ash whose character Paul Foreman was living with MND. Shelly was introduced as part of Paul's MND storyline, with the duo striking up a friendship at the hospital.

The weather was a huge challenge to Natalie and the team, with driving rain and wind making the route treacherous in parts. Parts of the cycle route were also closed which saw the distance increase to a gruelling 50 miles.

Natalie was inspired to take on the challenge after playing the part in the soap and finding out more about the devastation MND causes. She trained hard for the challenge and used a specially designed hand-cycle to complete the huge ride.

Natalie said: "Thank you to everyone who supported us and helped make Roll and Raise possible. We ended up doing 50 miles in the end. We had a few problems on the canal because of the weather. It was very muddy and there were some hairy moments but we got through it. Onwards and upwards for next year – let's together try to be part of the cure for an illness that takes so much from everyone."

Natalie Amber

Natalie has raised over £4,000 which will help those living with MND, and preparations are already beginning for next year's challenge which Natalie hopes will be even bigger and better.

Running home for Christmas

Kevin Sinfield CBE will lead his team in their fifth fundraising challenge in support of the MND community, this year titled 'Running home for Christmas'.

The week-long challenge will start on Sunday 1 December with Kevin and the team set to cover more than 50km per day, visiting seven regions across the United Kingdom. The team will start the penultimate leg at the Association's office in Northampton.

Our late MND Association patron and rugby league legend, Rob Burrow CBE remains at the heart of the challenge, with the £777,777 fundraising target inspired by his iconic Leeds Rhinos number seven shirt. The Association will receive half the money raised by the challenge.

Members of the MND community will have a chance to run with Kev and the team at set points during the seven days, reviving the popular Extra Mile events from last year's 7 in 7 in 7 Challenge.

More information about the challenge will be shared on our website and social media channels over the coming weeks, and you can support Kevin's efforts on his fundraising page: https://donate.giveasyoulive.com/fundraising/kevin-sinfield-and-teams-fundraising

Kevin Sinfield CBE with Buddy the Association's fundraising mascot

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Do you want to know more about MND research...
but not sure where to begin?

The research team is taking a 'back to basics' approach in a series of blog posts designed to break down scientific topics related to MND.

It is hoped the series will help the community build a foundation of knowledge to support understanding of the latest MND research.

The first part of the series includes information on MND, motor neurones, DNA, proteins and factors that contribute to the development of the disease.

Visit https://mndresearch.blog/category/back-to-basics/ to start your journey into MND research

Phang-tastic support
from celebrity chef

Our *Eating and drinking with MND* guide has been refreshed with help from celebrity chef and Association supporter Jonathan Phang.

For people with MND or Kennedy's disease experiencing swallowing difficulties, the guide offers information as well as a range of diverse recipes including a special contribution from Jonathan. All the recipes can be easily adapted to different consistencies by being chopped, mashed or blended according to your needs.

Jonathan said: "Culinary experts, health professionals and people with or affected by MND have created the recipes in this *Eating and drinking with MND* guide. It is an essential support to MND carers and a creative and resourceful cookbook you will treasure forever."

The full-colour, spiral-bound book has a wipe clean cover and there is also a companion web app so you can access recipes on your phone or laptop. The guide has been endorsed by the British Association for Parenteral and Enteral Nutrition (BAPEN).

5: Easy-swallow recipe

Shrimp creole

Jonathan's spicy recipe is as colourful and flavourful as the Caribbean itself. Although best with the spices, leave out the chilli and pepper sauce if these cause coughing.

Ingredients

- 2 tbsp mild olive oil
- 60g salted butter
- 1 onion, halved and thinly sliced
- 3 garlic cloves, finely chopped
- 1 green pepper (bell pepper), seeded and thinly sliced
- 1 Scotch bonnet chilli, seeded and thinly sliced
- 2 celery sticks, finely sliced
- 60g creamed coconut, cubed
- 1 tbsp smoked paprika
- 2 tsp garlic powder
- 2 tsp soy sauce
- 2 tsp Worcestershire sauce
- 2 tsp West Indian pepper sauce
- 1 tbsp tomato purée large pinch of sugar
- 400g tin can of chopped tomatoes
- 900g tiger prawns (shrimp), peeled and deveined
- salt and freshly ground black pepper
- finely chopped parsley and lemon wedges, to garnish

Method

1. Heat the oil and butter in a
deep frying pan over a med
2. When the butter has melted
garlic, green pepper, chilli a
cook for about 5 minutes un
3. Add the creamed coconut
until melted.
4. Sprinkle over the paprika an
Then add the soy, Worcester
sauces, tomato purée and t
cook for 5 minutes.
5. Pour in the chopped tomato
until the sauce has reduced
6. Finally, add the prawns and
5 minutes, or until cooked th
7. Depending on your swallow
serve with rice, chopped pa
lemon wedge.

Preparation time:
55 minutes

Serves:
6

PAGE 96 | Eating and drinking with motor neurone disease (MND)

Shrimp creole

Featured recipe from **Jonathan Phang**

Jonathan Phang is an experienced presenter, broadcaster, food writer and cook. Jonathan began his career in the 1980s managing some of the world's most influential fashion models, winning him a much-coveted role as a judge on the hit show *Britain's Next Top Model*. He also mentored disabled contestants on BBC3's ground-breaking *Britain's Missing Top Model* which won a RADAR Media Award for Best Factual Programming.

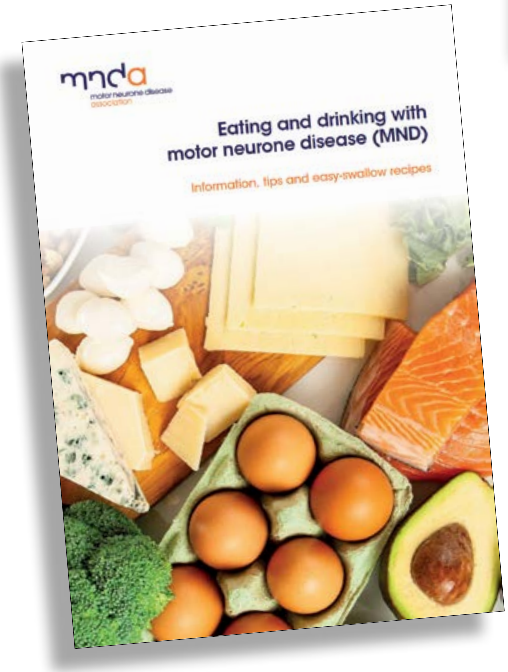
British-born Jonathan grew up in a mixed-race Chinese-Caribbean household, where his passion for cooking began as soon as he could pick up a mixing spoon. His cookbook, *The Pepperpot Club – A Celebration of Caribbean Cuisine*, was published by Hardie Grant and Rizzoli and nominated for an International Gourmand Award. Jonathan's recipes have appeared in countless international magazines.

A regular guest on *Market Kitchen*, Jonathan was also a news reader for DIVA Radio and television reviewer for BBC Radio London. For the Food Network and Travel Channel, Jonathan presented gastronomic travelogues called *Caribbean Cookbook* and *Gourmet Trains*. Recently, Jonathan has appeared regularly on ITV's *Love Your Weekend* and *Saturday with James Martin*.

See Jonathan's foreword for this guide on page 5.

"When my sister was diagnosed w
it was vital for me to offer her co
and a sense of security in the on
I knew how. I created recipes ba
on our favourite shared memorie
familiar and evocative flavours,
in my opinion, significantly impr
wellbeing and peace of mind."

Jonathan Phang



mnda motor neurone disease association

Eating and drinking with motor neurone disease (MND)

Information, tips and easy-swallow recipes

President of BAPEN, Nick Thompson, said: "This is a wonderful resource which will be hugely helpful for those with MND, family, carers and health care professionals – BAPEN are delighted and proud to endorse it."

In his foreword for the guide, Jonathan shares how he helped care for his sister. He writes: "When my sister was diagnosed with MND, it was vital for me to offer her comfort and a sense of security in the only way I knew how. I created recipes based on our favourite shared memories with familiar and evocative flavours."

British-born Jonathan grew up in a mixed-race Chinese-Caribbean household. He said: "Food became our parents' primary communication tool… and a solution to everything..."

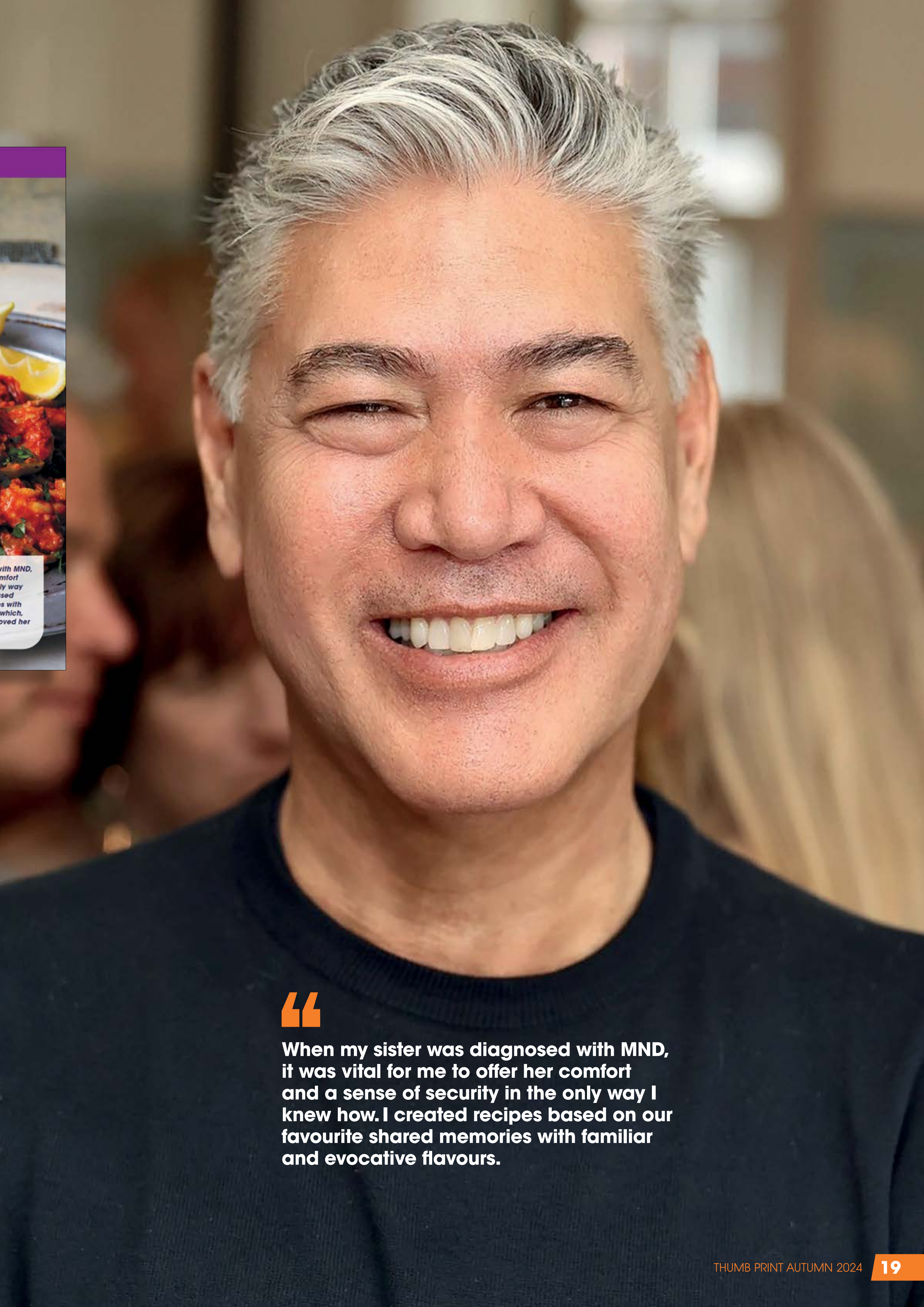
His passion for cooking began as soon as he could pick up a mixing spoon.

An experienced presenter, broadcaster, food writer and cook, in the 1980s Jonathan managed some of the world's most influential fashion models, leading to a role as a judge on the hit TV show *Britain's Next Top Model*. He also mentored disabled contestants on BBC3's ground-breaking *Britain's Missing Top Model*. Recently, Jonathan has appeared regularly on ITV's *Love Your Weekend* and *Saturday Morning with James Martin*. He also presented his own ten-part series Jonathan Phang's Caribbean Cookbook for Food Network and *Gourmet Trains* for Travel Channel.

> **“Culinary experts, health professionals and people with or affected by MND have created the recipes in this Eating and drinking with MND guide. It is an essential support to MND carers and a creative and resourceful cookbook you will treasure forever.**

Find the guide and companion web app online at: www.mndassociation.org/eating

Or order a printed copy of the guide from our helpline MND Connect, 0808 802 6262, email mndconnect@mndassociation.org



> When my sister was diagnosed with MND, it was vital for me to offer her comfort and a sense of security in the only way I knew how. I created recipes based on our favourite shared memories with familiar and evocative flavours.

Art therapy in practice

People with MND and their families living in Sussex and the surrounding area have been able to access art therapy sessions thanks to local branch support and an MND art therapy project.

Initiated by Debbie South, an MND specialist practitioner, with funding from the West Sussex South Branch, the project has recently been extended with further support from the East Sussex Branch.

Attendees have also become exhibited artists, with their work accessible online and at exhibitions such as the one hosted at Brighton and Sussex Medical School in July, pictured right.

Art therapist Adam Levene who runs the sessions said: "Art therapy can support patients, carers, and family members to find a voice by providing a therapeutic space that allows people to express things that might otherwise have stayed repressed. The art that gets made in art therapy goes beyond words but then, often, comes back to the words that need to be known, spoken and shared."

To view the exhibition and artwork visit www.bsms.ac.uk/research/neuroscience/sussex-mnd-care-and-research/index.aspx

Andy Sheppard

Andy Sheppard had reservations about his artistic ability and physical limitations when art therapy was first suggested to him. But the 41-year-old, father-of-three was keen to find ways to help improve his mental health. So he joined art therapy sessions.

Under the guidance of qualified art therapist Adam Levene, Andy learnt how to use tools and techniques to create art.

He said: "Art therapy is a way to share my emotions and experiences with my family without talking.

"It's a way I can share without promoting conversations and people can ask questions without fear of upsetting me. It creates a talking point around my illness and how I feel without the need to vocalise my suffering and pain."

Andy's wife Jodie said: "Art therapy has had a profound impact on Andy's psychological wellbeing. Through the process of creating art and reflecting on all his creations, he has gained an insight into his emotions, he's learned coping strategies for managing stress and anxiety and developed a greater sense of self-awareness and acceptance. As a family it also enabled us to work together on something creative with Andy."

Sam Whittaker

Art therapy can be an emotionally healing experience for the whole family as Sam Whittaker, who was diagnosed with MND last year, discovered. Sam attends sessions with husband Steve and daughters, Evie and Elise.

Sam said: "I wasn't very good at art when I was at school, but I've found comfort in being able to express myself through collages and pastels. It opened up new conversations with myself and my family about things we never talk about. I always leave brighter than when I arrived." Evie said: "We did a collage together. Mum wanted to co-create and I thought that was a really powerful way for us to communicate with each other about things we wouldn't necessarily talk about at home.

"The environment Adam created for us was so warm, welcoming and empathic and he gave us the space to express ourselves, and he'd listen to us. It never felt like he was probing too much, he manages to find the right balance of questioning things slightly to do with the art, but not overstepping any line."

for people with MND

PROMISE 3
WE WON'T REST UNTIL
EVERY DAY COUNTS

Sharon Hubbard

Sharon Hubbard who has MND, pictured above left, and Paula Jenkins heard about art therapy from their Association visitor. After some initial hesitancy from Sharon, they both now look forward to their sessions together. Paula said: "We started going once a week and slowly began to try watercolours, oil pastels and acrylic paint.

"Adam's approach was welcoming and encouraging, but also very calm. We'd sit and chat as well as draw. He would very carefully talk about things we'd been experiencing. He's been very strong in encouraging me to say what I want to speak about. In using the watercolour pencils and talking about our hopes and holidays, things that were annoying either of us we were able to talk about. Sometimes I can see something of what I've been talking about has come out on the page."

> **The art that gets made in art therapy goes beyond words but then, often, comes back to the words that need to be known, spoken and shared.**
>
> Adam Levene

Howard Chipperfield

Howard Chipperfield was diagnosed with MND last year and has been attending sessions alongside his wife Linda. Howard said: "My wife and I were struggling with the emotional side of MND. We were introduced to Adam and decided to give it a go.

"It was a bit of an unknown because we're not artists. I never really appreciated art before and what the power of it is. Drawing something that is heartfelt is quite a powerful way to highlight how you're feeling.

"Art therapy has helped us in understanding the impact of MND and on the emotional differences between myself and Linda. My fears revolve around my illness and how it will affect me, while Linda's art showed her fears about how and what she needs to do to support me later with my illness.

"During the therapy sessions conversations revolved around the two of us and highlighted the areas Adam could help us with. We now have a different outlook on MND. We appreciate the fight that's ahead and what other people are feeling. We can face MND head on and meet other people with MND and talk to them about what they are going through. It has broadened our outlook. If we'd been left to our own devices we would have struggled."

If you have MND and would like to create your own artwork at home, try Mind's Eye

Mind's Eye is a free to use app, developed with help from the MND Association. It uses artificial intelligence to help people with MND create images. Since its launch in 2022, over 2,600 people have downloaded the app.

Dr Rick Neims says creating art with the app helps him remain positive. said: "Retaining control, positive thinking and happiness all improve outcomes. On the really bad days, decide you're going to cry because that way you are still in control, and once you've had a good weep, mop yourself up, and get back to being positive and helping others."

If you would like to know more about the app please email mindseye@mndassociation.org or download the app free of charge at https://minds-eye.app

Artwork created by Dr Rick Neims

Community choir raises £20,000 for the MND Association

A choir in Wales called The Risca Male Voice Choir boosted its numbers and fundraising by recruiting members from the local community.

Vice Chair of the Choir, Tim Stone said: "We came up with something called 'The Project' which involved getting 50 male volunteers from the area to get together and form a 65-strong choir.

> **A few of our singers have family members or friends who have been affected by MND, and we know it's something that impacts the community of Risca too**

"They rehearsed for 12 weeks before coming together in Rougemont School and performing in front of an audience. They did two songs before Risca Male Voice Choir joined in. It was a great occasion."

The choir has raised over £20,000 for the MND Association, a charity which is 'very close' to a lot of the group's hearts. Tim said: "A few of our singers have family members or friends who have been affected by MND, and we know it's something that impacts the community of Risca too."

The choir attended Eisteddfod, a music and poetry festival with competitions and performances, where they were crowned the best choir in Wales. Tim said: "It was a phenomenal result. We hoped to place at best. A special mention has to go to our conductor Matthew Harrison, who won best conductor of the competition."

With more members expected to join after the summer period, Mr Stone and the choir are excited about the future of the group, which rehearses twice weekly at Choir HQ in Risca.

CARE INFORMATION UPDATES

Eating and drinking guide

Providing information, tips and easy-swallow recipes, our *Eating and drinking guide* (page 18) has been refreshed and updated. See the guide and more at: www.mndassociation.org/eating

The following information sheets and other resources have been updated.

1D *How we use your information*
3D *Hospice and palliative care*
6B *Complementary therapies*
10G *Support for families*
What is MND? Animation

See the option for Information sheets at: www.mndassociation.org/careinfo

See our animations at: www.mndassociation.org/animations

Revised information for professionals

We also offer resources to health and social care professionals, to help them provide tailored support. The following items have been updated:

Support for health and social care professionals guide
Our guide about support that MND Association can provide to health and social care professionals.

Information sheet P2 - *Wheelchairs for people with MND*
Information for professionals about access to wheelchair services and the types of wheelchairs recommended for people with MND.

Information sheet P13 - *Using our care information resources*
This sheet explains how professionals can find and order our resources, with guidance on what information to provide at diagnosis.

See all of our resources including those for professionals and researchers at: www.mndassociation.org/publications or order printed copies from our MND Connect helpline: 0808 802 6262, mndconnect@mndassociation.org

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

Trusted Information Creator
Patient Information Forum

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 2024-2025. If you would like to get involved, there are opportunities to feed into a range of different content and formats.

You can pick and choose which tasks you want to work on and make a difference from the comfort of your own home.

To find out more, contact: infofeedback@mndassociation.org

David’s legacy continues to fly

Kite flying added to fundraising efforts

David Greaves was just 30 when he was diagnosed with MND. Its rapid progression cruelly prevented him from realising many of his life goals, including raising a family of his own in the Peak District. However, the ultra-marathon runner and Iron Man triathlete was determined to make the most of the time he had left.

David faced MND with courage and humour, and refused to let MND destroy all his dreams. An aspiring author, after diagnosis David left his job and spent the last year of his life working on a delightful collection of stories for children.

David Greaves

Following David’s death just 15 months later in September 2016, his parents Andrew and Sarah, elder son Peter and David’s wife Philippa, set up Stanage Press Ltd to publish David’s books.

Andrew said: “We miss David greatly, but his legacy lives on in his wonderful stories. At first David used his phone to write the stories, but as his MND progressed we got him an Eye Gaze computer, enabling him to write until the very end.

“It’s comforting that David lived to experience the satisfaction of being acclaimed as a writer. His first book *Philippa and the Homeless Bumble Bee* was published by Friends of the Earth. Before he died, David asked us to ensure the rest of his books were published too.”

Left to right: Philippa, David’s wife, brother Peter and parents Sarah and Andrew Greaves completing an MND fundraising challenge

Stanage Press was named after David’s spiritual home, Stanage Edge in Derbyshire, which is where the family scattered David’s ashes. The family have also continued David’s fundraising for Team 2Fingers2MND, which started with David and Philippa’s Mount Kilimanjaro climb. The totaliser now stands at over £109,000 thanks to continued fundraising by David’s family and friends.

Andrew said: “Publishing David’s stories for him has helped us grieve his loss. Hearing how much both parents and children love David’s stories continues to lift our spirits. We think about David often and the journey that we went on with him. We are so proud of David and the dignified way he coped with MND. He wasn’t bitter or angry, and he never lost his sense of humour. He put huge effort into making people feel better. With Eye Gaze helping him deliver his witty one liners, you’d hear gales of laughter from visitors right up to the very end.

“Some months after David’s death, Sarah and I were walking by the sea, feeling a bit down, when we came upon a rainbow kite lying tangled up on the beach. It flew as soon as we picked it up. The kite felt like a gift from David and we could almost hear him telling us to cheer up! When the MND Association was looking for new activities to raise funds and awareness, the idea of a mass kite-flying event seemed perfect.

“We held the first kite event in 2023, and it now looks set to become a regular fixture. Kites are wonderfully inclusive because even those who use a wheelchair can get involved. I hear that local MND Association branches and groups elsewhere are planning similar kite-flying days, which is lovely.

“We were all devastated by David’s death but everyone who knew him has turned his loss to MND into something positive. The books, the annual kite-flying celebrations and our treasured memories of him all keep David’s spirit alive and flying high. He deserves nothing less.”

Kite flying event to raise funds and awareness

> **“At first David used his phone to write the stories, but as his MND progressed we got him an Eye Gaze computer, enabling him to write until the very end.**

If you would like to find out more about David’s books visit stanagepress.com

The company we keep
Donations, fundraising and volunteering

We're lucky enough to enjoy good company at the MND Association, with many local and national companies supporting our work.

Through donations, fundraising and volunteering, companies support the MND Association's mission to improve access to care, research, and campaigning for people living with or affected by MND.

Here is a round-up of how some companies are contributing to our fight against MND.

The Campions Group

Property sales and lettings agents Campions Group selected the MND Association as its charity of the year. In July, 26 colleagues from Campions took on the Yorkshire Three Peaks to raise money for the charity.

The one-day trekking challenge took the team to the summits of Pen-y-Ghent, Whernside and Ingleborough, in one circular route starting and ending in Horton-in-Ribblesdale all within 12 hours.

This challenge required the team to support each other every step of the way which included 1,700m of ascent. They raised £11,000 for the MND Association. In total Campions have so far raised more than £16,000 and plan to do another fundraising challenge later this year.

Dell

Twenty teams from across the IT Industry took part in this year's Dell Technologies Management Challenge, pledging more than £70,000 for the MND Association – the highest total in the event's history.

In June, teams mountain biked, hiked and ran through the stunning surroundings of Bannau Brycheiniog, Brecon Beacons National Park, while testing their map reading, communication and team working skills.

Dell's team, Dragon's Breath Brigade, won the fundraising award for raising £6,750 between them, and they were also crowned the winners of the weekend, completing the challenge in the fastest time.

Event partners included LinkedIn, Brecon Carreg and High 5 nutrition, with the event organised by Run 4 Wales, which is also partnering with the Association this year.

Rendall and Rittner

Rendall and Rittner, which provides property and building management services, nominated the MND Association as its Charity of the Year in February following a staff vote. MND has sadly touched some colleagues so the team are very passionate about supporting the charity.

Colleagues have joined forces to volunteer for the Association and recently helped out at the Hayes Davison 5km run at Hyde Park (pictured). The team is also working hard to raise money and have so far raised over £15,000.

LEJOG Challenge

Inspired by his friend Paul Cook, who died from MND in 2022, and to achieve his lifetime ambition, Graeme Watt led a team of six riders to complete the Land's End to John O'Groats (LEJOG) Cycle Challenge over 12 days.

Joined by friends and colleagues from the IT industry, including Dell and HP for some of the days, the team raised more than £200,000 by completing the challenge. Faced with weather ranging from heatwaves to heavy rain, the team crossed the finish line on schedule, arriving at John O'Groats some 12 days after leaving Land's End.

From organising fundraising events, to signing up to payroll giving, there are lots of ways for companies to give back and support the MND community. If you would like to chat to the team about a potential corporate partnership please email corporate@mndassociation.org or call 01604 611888.

Part of the Campions Team at 3 peaks challenge

Dell technologies Management Challenge 2024

Rendall and Rittner volunteers at HD5K

Graeme Watt and Team LEJOG

Walking to d'feet MND
Fun and friendly walks raise funds


Tyne and Wear Group


Norfolk, Norwich and Waveney Branch


South West Wales Branch


South Yorkshire Branch

> **It was a lovely chance to bring together lots of those who have been touched by MND in the North East. A relaxed atmosphere where people can bond and share their stories.**
>
> Dominic McDonough
> Regional Fundraiser for the North Region


Coventry and Warwickshire Group


Hertfordshire Branch

Whether it's a countryside ramble or a walk along the coast with some four-legged friends, *Walk to d'feet MND* events are a fun and family-friendly way to help raise funds for the Association. No matter how short or long the walk is, our members are making a difference – a sea of walkers in blue can't be missed!

Many of our branches and groups have been busy organising events over the summer.

Tyne and Wear Group

Over 80 people from across the North East joined the Tyne and Wear Group Walk to d'feet MND at the seaside resort of Whitley Bay. Bringing together people affected by MND and Association supporters, the group walked two and a half miles from Whitley Bay to St Mary's Lighthouse and back. Braving the baking heat, the walkers were met by volunteers with refreshments and stopped for a picnic at the halfway point. Raising both awareness of MND and around £800 for the local group, many participants commented that this was the first event that they had been to, but that it would not be their last.

Coventry and Warwickshire Group

Many of us bring our dogs with us on our walks, but dinosaurs? Pictured above are Madge and Nellie, two friendly dinos that helped the Coventry and Warwickshire Group make a roaring amount of money on its annual walk at Ryton Pools Country Park in June. In total, 148 people – and 15 dogs – turned out for the best-attended walk yet, raising £1,110.

Norfolk, Norwich and Waveney Branch

The good old British weather couldn't hold back 52 intrepid walkers from taking part in a walk to raise funds for the Branch, along the prom from Hunstanton to the village of Heacham and back. The forecast for heavy rain throughout the morning didn't quite come to pass and a good time was had by all. The Branch raised £655.

We love seeing your Walk to d'feet MND photos. If you have any events coming up in your communities, please email them to editor@mndassociation.org

Annual Stephen Hawking MND Lecture to focus on the psychological impact of MND

Booking is now open for the MND Association's 2024 Annual Stephen Hawking MND Lecture.

These prestigious annual lectures present current research on MND to professionals who work within multidisciplinary teams, and demonstrate how this research can inform and enhance their practice. The online lecture will be held on Tuesday 12 November, from 6pm to 8pm, and is free to attend.

This year's lecture will focus on the psychological impact of MND, highlighting the role of Acceptance and Commitment Therapy (ACT) in improving the quality of life for people with MND. ACT is a type of mindful psychotherapy that helps people stay focused on the present moment and accept thoughts and feelings without judgment. Attendees will gain practical insights into how ACT principles can be integrated into their professional practice.

The session will be led by Rebecca Gould, Professor of Psychological Therapies in the Division of Psychiatry at University College London and an Honorary Clinical Psychologist in Camden and Islington NHS Foundation Trust.

Professor Gould will provide an overview of ACT and present findings from the groundbreaking COMMEND research study, which investigated the effectiveness of ACT for people living with MND. She will also discuss the psychological support needs of people with MND and review available psychological therapies, in line with the NICE Guideline on MND. She will demonstrate how health professionals can apply ACT principles to their everyday practice.

This event is open to all health and social care professionals, and members of the public with an interest in MND. Visit https://bit.ly/HawkingLecture2024 to find out more and book your place.

Chair's Message

Following an excellent and productive Annual General Meeting, the MND Association continues at pace to address the pressing needs of our community and help realise the emerging opportunities in research, treatment and care.

We are delivering this through our strategic plan aligned to our Promises. This includes the launch of a new MND Care Centre at St George's NHS Trust in London and the roll out of our Research Nurse Network.

Turning to team matters, I'm pleased to welcome two new trustees, Ed Cooke and Michael Hope, both of whom bring significant professional experience alongside the lived experience of MND. I'd also like to welcome back to the Board Alan Graham, a former Chair of the Association and Liz Ellis a much valued colleague.

On behalf of the Association and whole MND community, I would also like to congratulate our former Chief Executive Sally Light for the OBE she was awarded in the recent King's Honours. Sally gracefully said the award was for the MND community at large, but we all know the value she brought during her ten years with us. Finally, I would like to thank Kevin Sinfield CBE who has committed to his fifth challenge raising money for MND causes in memory of his late friend and team mate, Rob Burrow CBE.

Dr Usman Khan

Spotlight on our new trustees
Why they joined our board

The MND Association's Board of Trustees is responsible for our governance and strategic direction. The Board is accountable for everything we do and plays an important role in ensuring our charity is run in the interest of the people we are here to support. In June, four new trustees joined our Board, each with their own personal reasons for becoming an MND Association volunteer trustee.

Meet Ed

Ed Cooke is a lawyer who is living with MND. Following his diagnosis, Ed found the MND Association to be an essential source of information and support, so he wanted to give back to the charity. Speaking about his new appointment Ed, who is 49, said: "This gives me a real opportunity to make a difference to the lives of those afflicted by this disease both now and in the future.

"Living with MND, I've direct experience of the frustrating diagnostic process, shock of receiving the news, uncertainty of how and when the symptoms will develop, fear of the future and mixed feelings of regret and determination.

"Each person's journey following diagnosis is distinct. I believe it would be advantageous for the Association to have more trustees who are living with the condition, as they can offer invaluable first-hand insights. Coupling these experiences with those of existing trustees, many of whom have backgrounds in care-giving or possess medical expertise, will undoubtedly benefit the Association."

Meet Alan

Alan Graham MBE, retired director of a major UK merchant bank, first became involved with the Association when his late mother was diagnosed in 1989. He is a joint founder of the North West London Branch, where he is still Treasurer. A former Trustee of the Association, a position he held for 15 years (six of which he served as Chair), he was also the Association's Director on the Board of the International Alliance, for ten years from 2001. Alan is also a Trustee of one other national charity, and on the Board of his local hospice.

Alan said: "Having been connected with the Association, nationally and internationally, for over 30 years, and with my continuing involvement at branch level and elsewhere in the sector, I remain passionate about the organisation, its mission, objectives, and care and research agendas. I wish to continue to contribute to the achievement of the Association's vision of *a world free from MND*."

Meet Michael

Michael Hope, along with his family, watched his uncle's progression with MND until he died aged 83. This experience, combined with his own lengthy journey to get a confirmed diagnosis of MND, motivated him to stand in the trustee elections.

Michael said: "I watched my uncle progress with MND, becoming physically locked in, whilst his mind remained sharp until he was 83. For me, it took over eight years to receive a correct diagnosis. During those years I was sent on numerous specialist pathways. This gives me an understanding of the journeys people travel, either alone or with their families.

"I understand the difficulties for people living with MND and their carers. I've seen courage, bravery and perseverance which inspires me to stand to be of service to represent and speak for people affected by MND."

Meet Liz

Liz Ellis' son Stephen was diagnosed with MND in 2018. It progressed rapidly and he was hospitalised in August 2019. The following month, in order to save his life, he won a hard fought battle for the right to have a tracheostomy. Stephen sadly died in February 2024. Liz wants to use her experience to help others affected by MND.

She said: "I was truly pleased to be voted for a second term as a trustee of the MND Association. Stephen's path is not one that everyone with MND would choose but it was the right one for him. I want to use our experience to help others affected by MND navigate their own chosen paths. Stephen left me a legacy to fight for anything and everything to help everyone affected by MND, both in the future and the here and now. I promise my absolute commitment to the MND community."

Paul's Pushers raise £3,500

Team effort supports Paul

Paul's Pushers cross the finish line, raising £3,500

In a remarkable display of determination and community spirit, Paul Maddison, a former neurology consultant living with MND, participated in the Leeds 10k alongside his family and friends.

The team, affectionately known as 'Paul's Pushers' raised over £3,500 for the MND Association. It was a real team effort, comprising of Paul, his wife Lisa, son Ben, daughter Laura, brother Barry, niece Lucy and two friends and fellow medics, both called Tim.

> **It was great being part of a run again and having the chance to feel normal.**

Together, they pushed Paul in his specially designed running wheelchair, part-funded by the MND Association and Challenging MND. Paul, an avid runner before his MND diagnosis said: "It was great being part of a run again and having the chance to feel normal. The buzz and the cheers from the crowds and the other runners were amazing – I loved it."

The team are already planning to take part in Park Runs and hoping to join in the Great North Run in 2025 to raise funds for the Association.

Rust Bucket Rally

The Rust Bucket Rally team with their cars

A team of car enthusiasts drove over 2,500 miles across Europe in cars worth less than £500.

The Rust Bucket Rally, which is organised by Carlos Baldry, is an annual fundraising event which sees teams drive across Europe in just four days.

Now in its 10th year, the event takes place every June raising money for various charities. This year, 56 cars travelled through England, France, Monaco, Italy and Switzerland, raising more than £43,000 for the MND Association.

In July, members of the Rust Bucket Rally team visited the Association's national office at Northampton's Moulton Park to learn more about the impact their fundraising is having on the Association's work. The money will contribute towards research into potential new treatments.

Carlos said: "It has been incredible to visit the Association to find out more about the incredible work it does to support people living with MND. The rally started from a simple idea inspired by the film Cannonball Run and the TV show Top Gear, it then very quickly gained traction among friends and continues to grow today.

"The charity element comes from our rugby connections. We've been inspired by Rob Burrow's story and Doddie Weir came to Old Grammarians in Wellingborough, so we've all been touched by their stories.

"At the end of the day, we just go out there and have a laugh, but to understand the difference we're making is just incredible. It makes everything worthwhile."

The Association's Director of Income Generation, Jo Coker said: "It has been an absolute privilege to meet the team, see some of the cars and to thank them personally for their efforts and the incredible amount they have raised for the Association.

"This money is so important to people living with MND and their families and will help us to provide care and support, while funding research into potential new treatments. We are so grateful for everything they have done to support us."

Magical moments and memories at Peppa Pig World

A day at Peppa Pig World for families affected by MND has created memories that will not be forgotten with vital awareness also being raised.

On 25 July, almost 100 people were greeted at the entrance of Paulton's Park in Hampshire – official home of every child's favourite pig – by local MND Association volunteers. Their tickets, funded by the MND Association, covered a whole day of fun in the Park, lunch, an array of craft activities and the opportunity to meet other families and children affected by the disease.

There were also goody bags, containing MND Association t-shirts to wear in the Park, a water bottle, stress balls and a gift card to spend in the shop.

Despite torrential rain, the great British weather did not spoil the event and there were many people in blue heading around the Park in waterproof ponchos.

Jeff McGuinness, who attended the day with his family, said: "Thank you so much for a great, albeit wet, day. The memories that were made will not be forgotten."

Caroline Motson added: "Thank you to you and the team for organising this day out. My mum had a wonderful day with her grandchildren - it's the first time she's smiled in weeks. Additionally, the support you have shown my eight-year-old daughter with the resources you've sent in the post and have available online have made all the difference.

"She spends considerable time supporting me to care for my mum which is a lot for anyone, let alone an eight-year-old. She's even found the confidence to talk about MND in her school assembly to raise awareness. Thank you for all that you do to help families living with MND - you're amazing."

> **"The feel of the day was great and there was so much sharing of experience and support, but also laughter and fun.**

The family day also provided an opportunity to raise awareness, with an Association stand at the entrance giving visitors to the Park chance to ask questions and donate.

Laura Willix, Children and Young People's Service Development Manager at the MND Association said: "The feel of the day was great and there was so much sharing of experience and support, but also laughter and fun. Never underestimate the power of just being with others who are in the same situation as you and the strength this can bring.

"One of the highlights was seeing a family whose grandmother has MND and uses a wheelchair, doing the conga with her children and grandchildren in the rain.

"The volunteers were exceptional, and we couldn't have done it without them. They helped supervise the rooms, direct families and stayed all day."

Emily Akerman, Children Young People and Families Project Worker, added: "The weather just became an added team member who helped prove just how resilient the MND community are. It could have been thunder and lightning or golf ball hailstones and I bet they still would have been out there making memories - it was an incredible day.

"I want to thank the volunteers for all their efforts in making the day possible and I hope that everyone who attended had a great day."

Ready, steady, bakeit!
Plan an autumn bake sale

With the nights drawing in, and festivals including Diwali, Halloween and Christmas on the horizon, it's the perfect time to get baking.

As well as being a time of celebration for many, it's also the perfect time to get ahead with baking homemade treats, particularly Christmas cakes and puddings.

This year, why not use your cookery skills to raise money for the MND Association at the same time by hosting your own autumn bakeit!? Swap a summery afternoon tea for a Halloween party, complete with gooey chocolate brownies and perfect pumpkin pies, or get ready for Christmas with a bake sale at work with mountains of mince pies, a spectacular stollen or a decadent chocolate yule log.

Sweetmeats, cookies, samosas and bhajis are also great to share, with sausage rolls, pasties and pies for those who prefer savoury over sweet. With every penny you raise supporting people with MND, their families and carers across England, Wales and Northern Ireland, there has never been a better time to get involved. Add friends, family and your favourite recipes for a fundraising event to remember!

To get your event up and running visit www.mndassociation.org/bakeit and register for your free fundraising pack, full of information to help get you started.

Celebrity chef and television food presenter, Matt Tebbutt

Celebrity chef Matt Tebbutt has kindly shared his recipe for Seville Orange Marmalade Tart. This sweet treat is perfect for your autumn coffee morning, afternoon tea party or bake sale.

Matt said: "I'm delighted to support the MND Association's 'bakeit!' fundraiser, and I hope that you will enjoy making my delicious recipe, while raising lots of money for this very important cause."

Matt Tebbutt's recipe

Seville Orange Marmalade Tart

Serves 4-6

- 20cm pastry tart shell, uncooked
- 2-3 tbsp good quality Seville orange marmalade
- 30g flaked almonds
- Clotted cream, to serve

For the frangipane:

- 250g unsalted butter
- 250g caster sugar
- 250g ground almonds
- 4 medium free-range eggs

To make the frangipane, beat or cream the butter and sugar in a food processor until the sugar has dissolved and the butter is pale. Turn the food processor speed down and add the ground almonds. Beat until just incorporated, then add the eggs one at a time so the mix doesn't split. Chill the frangipane until ready to use.

Preheat oven to 150 degrees C/300 Fahrenheit/Gas 2.

To assemble the tart, spread the marmalade on the base of the tart shell. Cover with the frangipane, sprinkle over the almonds and bake in the preheated oven for 40 minutes or until the frangipane is set (an inserted knife comes out clean).

Serve warm with a dollop of clotted cream.

Christmas Concert
in aid of the mnd association

Save the date

This December, the MND Association invites you to a truly memorable evening of music, hope and harmony.

Our inaugural Christmas Concert will be a joyful celebration, bringing the MND community together inside the beautiful St Mary's Church in Marylebone, London on the evening of Thursday 12 December. The concert will feature Christmas songs and carols led by the renowned London International Gospel Choir, and readings from some very special VIP guests.

Tanya Curry, Chief Executive of the MND Association said: "At this special time of year we are very much looking forward to bringing our community together for an entertaining evening of songs, readings and festive cheer in the most beautiful of settings.

"As well as uniting to enjoy this magical event, we will be raising awareness of MND and the work we are doing to support this truly wonderful community, and to reflect on the past year. We do hope you will join us for what promises to be a most enjoyable, heartfelt evening."

After the concert, seasonal refreshments will be offered, and there will also be an opportunity to buy some last minute Christmas goodies.

To find out how to secure your ticket, please visit www.mndassociation.org/christmasconcert

Make a date to join Team MND

Are you ready to join one of the most dynamic and supportive fundraising communities in the UK where even the smallest action can have the biggest impact?

This coming January it's time to join Team MND – a community of fundraising superstars all united behind one clear vision: to beat MND one step at a time.

With a wide range of fundraising events designed to suit people of all ages and abilities, there has never been a better time to join us. So, leave your excuses behind, bring your ideas and your energy and let the start of the new year be your inspiration to get involved.

Senior Engagement Fundraiser, Julia Beales said: "If you're looking for ways to fundraise in 2025 and want to show your support for people living with MND at the same time, we would love to hear from you.

"Whether you're a keen quizzer, an adventurous trekker, a runner or someone who wants to skydive for the first time, we have an event which is perfect for you.

"Every penny you raise will make a tremendous difference to the lives of people who are living with MND, their families and carers, allowing the MND Association to fund care and support as well cutting-edge research into new treatments and a cure.

Seema Sharma-Garosi ran the Cambridge Half Marathon to raise over £1,600

"And for those looking to get a head start on those new year's resolutions, our fundraising events offer the perfect chance to really challenge yourself and make memories to last a lifetime.

"With Team MND there are no limits – and we'll be with you every step of the way."

For more information about how to fundraise in 2025 stay tuned to the Association's social media channels or visit www.mndassociation.org/get-involved/fundraising

Run 60 miles
August challenge round up

August was a tough but rewarding month for the team of fundraisers taking part in our Run 60 Miles in August challenge. Over 4,400 people signed up and together they raised a phenomenal £650,000.

The participants all had different reasons for getting involved. Some relished the thought of a personal challenge, while others used the opportunity to get their children exercising over the summer holidays. But the participants had one thing in common; a desire to raise funds and awareness in the fight against MND.

> **“**
>
> **I see what effect this debilitating disease has on our patients and their families on a daily basis.**

Many shared stories in the dedicated Facebook group about their loved ones and how the disease had touched their families, friends and communities. Countless others were inspired to take part following the death of Association Patron, Rob Burrow.

Marsha Chant, who is an MND Co-ordinator based in Somerset, signed up and decided to powerwalk the 60 miles. Marsha said: “I see what effect this debilitating disease has on our patients and their families on a daily basis.”

Marsha hopes the money she raised will help fund research to find a cure and fund financial support grants. She said: “I know the MND Association has been so generous to the people I support, which gives the patients and their families something to look forward to. They’ve enabled our patients and their families to go away on holiday, enjoy spa days, have holistic treatments; the list is endless.”

Throughout the month participants diligently tracked their miles, with many even increasing the target distance for a tougher challenge. By the time the challenge finished on 31 August, the team had logged over 111,000 miles.

Marsha Chant who powerwalked her way through August

‘As the challenge came to a close, Rachel who took part in memory her friend Deb, shared; “I thoroughly enjoyed the challenge, it was a great way to get back into running, after focusing more on the walks this year. As aways the TeamMND community have been outstanding, the support from the admins, and the whole set up has been first class.”

Manette becomes
Britain’s oldest skydiver at 102

Fearless Manette Baillie marked her 102nd birthday with a skydive to raise money for the MND Association and two other charities. The Second World War veteran who served with the Women’s Royal Naval Service (Wrens), flew into the record books as Britain’s oldest skydiver following the 13,000 feet jump above Beccles Airfield.

Once safely back on land Manette said: “It was a bit scary. I must admit I shut my eyes firmly, very firmly. I just want to tell people getting near 80 or 90 don’t give up anything. Just keep going. 40 years ago, my friend told me, ‘Manette, never give up until you’re forced to’ and he was well into his 90s. I’ve never forgotten his advice.”

Manette landed to cheers from a crowd of friends and well-wishers who wanted to support her incredible fundraising, raising over £11,000.

Since then, Manette has been in demand, appearing on the BBC, *Good Morning Britain* and news channels in America. Her efforts have also inspired others to join the fight against MND.

Iris Penny, who is 86, contacted the Association to say that she had pledged to donate £10 to the MND Association every month after being inspired by Manette’s story. She said: “What an inspiring woman! I’m only 86 but not as brave as she is. Please give her my thanks and admiration.”

Friends and well-wishers who supported Manette during her skydive challenge

Life in the Sheila, Nigel and MND household

Nigel Daniels shares an optimistic and personal account of the life he shares with his wife Sheila and MND

YOUR STORIES

My wife Sheila has always been an active person, from working in the house and garden to trekking in the Swiss Alps. We've spent many happy times walking across high altitude snow fields and glaciers in glorious sunshine.

Sheila's tiny feet would grip the crumbling pathways like a mountain goat, whilst I would be fumbling for a sure foot-hold with my size 11 plodders. MND has not changed that dogged determination. Sheila and I have just adapted to a new way of life. After almost 52 years of marriage, it is still the same book, just another chapter.

Culinary alchemy

Sheila is a marvellous cook and, as we are both vegetarians, preparing a meal is very time consuming and with the onset of MND, it now takes even longer. I've rebuilt the kitchen to be wheelchair friendly, which enables Sheila to conduct her culinary alchemy in a comfortable manner.

Our son Phil and his partner Linda are continually discovering different aids and gadgets to assist with daily life. From handled bath sponges to easy-to-use can openers, they've found just about everything possible to make Sheila's life a little easier. The 'tilting kettle' is superb and requires very little effort to pour hot water.

MND continually presents new challenges to be addressed, which we do in the same manner as all of the other issues we have been confronted with over our many years of marriage. We find alternative ways of doing things, or accept that certain things can no longer be, and move on from there.

MND is a cruel disease, and does not like to be confronted, but that is exactly what it gets from us. MND may at this moment in time be unmastered, but it can be trained and tamed to a certain degree. And every day, I'm humbled by Sheila's defiant determination to fight against every obstacle that the world has decided to bestow upon her.

We, like many others, are disillusioned as to why a person that is diagnosed with MND, after their pensionable age, is not entitled to the same level of disability benefits as one who is diagnosed prior to that date. The same illness, the same issues, the same needs, just a different age. An unacceptable discrimination, considering that the older person has been contributing to the 'system' to the same extent, but for even longer. Hopefully, one day this issue will be addressed, and every person with MND will be treated equally.

A burning beacon

The MND Association has helped us in many ways. The devotion of the charity's volunteers is humbling. Sadly, our Association visitor, Clare Williams died last year. Clare was a burning beacon, and one of the greatest ambassadors the MND Association could ever wish for. All of the time that she was caring for Sheila and other people with MND, she was personally fighting her own illness with cancer. It brings a tear to my eyes as I type this script, to remember that Clare was personally fighting her own illness, whilst striving to make other people's lives a little more comfortable.

Nigel and Sheila trekking in the Swiss Alps

The MND Association contributed towards the elevation function of Sheila's neuro wheelchair. I'm a strong believer in looking into people's eyes as they talk. To that end, instead of being addressed from above, the elevated seat enables Sheila to have direct eye-to-eye contact.

The MND Association also substantially contributed towards a rise and recline armchair for Sheila and has enabled us to spend a few precious days away with Phil and Linda.

As time has progressed, so have the effects of the MND, to such an extent that it takes Sheila a long time in the morning to wash and dress. Sheila's determination to keep her dignity means that she wants to do everything that she can, while she can, regardless of the time limitations. A sentiment that we both strongly believe in.

This little insight into our lives would not be complete without acknowledging our sincere recognition and gratitude to all the wonderful supporters. They've enabled people with MND (like us) to access vital equipment and services and help fund research. Their generosity will put MND into the history books.

If anyone reading this has recently been diagnosed with MND, we sincerely hope that you manage to find 'your' way through it. The quality of your future depends on how you address the situation. You are never alone, although it may sometimes feel that way. Please do remember the MND Association and others want to help, so do let them.

Support our BBC Lifeline Appeal on television this October

Awareness of MND and the work of the Association will receive a boost this autumn, thanks to a BBC Lifeline Appeal.

The four-week fundraising appeal opened on 6 October and includes a televised ten-minute programme which will be broadcast on Sunday 13 October, repeated on BBC2 the following week.

> **I know first-hand from my family experience just how cruel MND is and why it is so important to help continue the MND Association's work, funding vital research and supporting families affected by this terminal disease.**

Viewers of the programme will hear from people affected by MND who will share their experiences of the disease and its impact, and how the Association has been able to support them.

Presenting the Appeal is radio and television presenter Charlotte Hawkins. A dedicated patron for the Association, Charlotte's connection to MND began when her dad Frank was diagnosed with the devastating disease in 2011. He died just four years later.

Charlotte, who presents on ITV's *Good Morning Britain*, Classic FM and ITV Racing, said: "I'm incredibly proud to present the MND Association's BBC Lifeline Appeal. I know first-hand from my family experience just how cruel MND is and why it is so important to help continue the MND Association's work, funding vital research and supporting families affected by this terminal disease."

Look out for more information about our BBC Lifeline Appeal on our social media channels, and please help us spread the word by watching our appeal, sharing with your networks or by making a donation. Visit www.mndassociation.org/bbclifelineappeal to get involved.

700km in 7 days
Suffolk to Cornwall trike trip

Keen walker and cyclist Nick Apperley shares how his MND diagnosis has provided new opportunities.

Embarking on a challenge to raise money for charity had been part of my future plans. My MND diagnosis provided an ideal opportunity to make it happen.

Sadly, the progression of my MND meant walking and cycling challenges were now out of the question. I discovered ICE trikes and after a test ride decided on an E-assist, automatic trike. Supported generously by family and friends via a GoFundMe page, plus with donations from the MND Association, the My Name'5 Doddie Foundation and Challenging MND, my trike was delivered in January 2024.

Having relished my boyhood in Cornwall, then happily living in Suffolk for nearly 40 years, I decided to ride 700km from Suffolk to Cornwall. On Sunday 9 June I set off from Suffolk on my '700km in 7 days' challenge cheered on by 200 people with klaxons, hooters, whistles and cheers ringing in our ears. Seven days later we finished among another lively crowd of supporters in Cornwall on Saturday 15 June.

Nick Apperley and supporters

Over the week we had the enormous pleasure of at least 50 different cyclists joining us along the way, and more than 50 friends and family meeting up with us for some very lively evenings - and a celebration of life and friendship.

While the prognosis is rubbish, I'm determined that my MND will not be life defining, that I can remain 'me'. I hope that by concentrating on the things I can do, rather than reflecting on what's gone, it will, for Jill, our boys, family and friends, ease the difficulties of seeing me with MND, and enable the continuation of our happy memories of our lives together.

I'm delighted to have raised over £37,000 towards my target of £50,000 for the MND Association, the My Name'5 Doddie Foundation and Challenging MND.

'This Tribute will last forever.'

Anne Cruickshank set up a Tribute Fund in memory of her mum, Barbara, who died of MND in 2010.

Three years later, Anne's dad Jeff died, so she decided to add his name to the Tribute Fund too.

Barbara and Jeff French

Anne said: "It is a comfort to know they are together again, and the fund will maintain the memory of our parents for future generations."

Barbara was diagnosed with MND in 2009 and died just a year later. Anne and her husband, Ken knew very little about MND at the time, but decided they would start raising funds for the MND Association. Together, they walked the full length of Hadrian's Wall in four days and raised £1,000.

Anne set up the Tribute Fund in memory of her mum, inspiring other family members to make regular donations via the online Tribute Fund page. Anne said: "As we have relatives all over the world, the page allows us to stay in touch with other family members, which helps with the grieving process."

"I find the Tribute Fund a very peaceful place to go, it is very comforting knowing that you can light a candle, or share a thought not only for those special occasions but just for no other reason than you are thinking of them, it somehow makes you feel more connected to them."

The Barbara and Jeff Tribute Fund has raised £9,068.

You can set up a Tribute Fund in memory of a loved one today. Visit www.mndassociation.org/tribute

Thank you

to all our fundraisers

Share your pictures at **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.

£7,500

Hair-razor

Ada Barstow-Bray, 15, shaved her hair off to raise money for the MND Association following her mum Emma's diagnosis last year. Ada said: "My hair is a big part of my personality. I hope that by sacrificing it, I can make a difference and fight against the disease stealing Mum from my brother and me."

For David

Beverley Rudland completed the 311 mile London to Paris cycling challenge in memory of her husband David, raising a brilliant £4,000 for the MND Association.

£4,000

£57,000

Cycle Cambodia

After 36 years together, Bridget Steward set out on a solo adventure in memory of her husband Mark, who died last year from MND. Travelling alone for the first time, Bridget cycled 391km over six days from Ho Chin Minh City in Vietnam to Angkor Wat in Cambodia. Together Bridget and their four children have raised over £57,000 in memory of their much loved dad and husband.

£3,100

Miles for Mary

John Liberty walked the length of Hadrian's Wall Path, totalling 135km in honour of his sister Mary, who is living with MND. John's family, friends and walkers he met along the way helped him raise an incredible £3,100.

From Suffolk to Spain

Steven Howe cycled from his home in Suffolk to Spain in memory of his wife Rachael, who died from MND two years ago. Steven raised a fantastic £6,000 for MND research and his local Suffolk Group.

£6,000

£1,200

Remembering rugby legends

Seven-year-old rugby fan James Smith took on the Three Peaks with his dad Martin, to raise money for the MND Association. James wanted to raise money after being inspired by Rob Burrow CBE and Doddie Weir OBE. Martin said: "James is an incredible, brave, strong young man I'm so proud of."

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**

£1,390

7in7 challenge

Nine-year-old Lyla Ostermeyer took on a different physical challenge each day for seven days to raise an incredible £1,390. Lyla cycled, skipped, scooted, swam, trampolined, ran and canoed her way through the challenge in memory of her grandad who had MND.

£20,000

Blockbuster for brother

Henry Lumby completed a series of bike rides he called 'The Blockbuster Challenge', totalling over 1,000km in honour of his brother Hugh, who is living with MND. The name of the challenge was in recognition of Hugh's appearance on Bob Holness' iconic quiz show in 1985, when Hugh was 18.

£3,000

Pounds for lbs

Andree Graham set herself a challenge to lose weight before the end of the year following her fiancé Ian's diagnosis of MND. Andree's weight loss will support others affected by MND while also leaving her fitter and stronger to care for Ian in the future. She's well on her way and has already raised over £3,000.

£8,000

Janice and friends

Janice Barnstorm and her friends completed a series of walking events during June. Despite her MND diagnosis in March 2023, Janice completed her own half marathon over a week. Janice said: "I can no longer speak to say thank you, however I hope everyone knows just how much the support means. My attitude is fight, fight it all the way and never give up hope."

£847

Footie for Dad

Graeme Morris organised a football tournament to remember his dad, Andy, who died from MND five years ago. Family and friends competed in the Andy Morris Memorial Shield raising over £800 for the MND Association.

£7,000

Pub crawl

Two local pubs organised a half marathon walk to raise money for the MND Association in memory of Rob Burrow CBE. Walkers set off from O'Gradys in Redcar and walked the seven mile route along the North Yorkshire coastline inland to the Miners Arms near Saltburn where they were rewarded with a pint. Following the success of the event, raising over £7,000, it's now set to become an annual tradition.

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 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,

If you only had 1,000 words left what would you say?

That was the question I asked the audience while performing at the Ramsgate Festival of Sound. My '1,000 words' festival performance was recently featured in an ITV Anglia news series called Speechless.

MND has taken away my voice but I'm grateful I managed to bank it before that happened. Despite my MND, I'm determined to live as positively as I can. As for my own last words, they'd be 'I love you'. I think everyone would probably say that!

Mike Willis

(Editors note: Visit Mike's You Tube channel to watch recordings of his 1,000 words performance. Simply search for Mike Willis, 1,000 words)

Christmas card reminder

With Christmas fast approaching, don't forget to order your Association Christmas cards in time for posting. Remember every penny of profit, together with any donation you wish to make, goes directly towards improving the lives of all people affected by MND.

Order online at https://shop.mndassociation.org no later than 2 December

A small selection of cards available

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.

Dear editor,

I wanted to share with you and the MND community a special moment my grandsons experienced.

Harrison and Jake's school nominated them for 'The Charity and Community Award' for their fundraising for the MND Association. We were all so proud to learn they had been shortlisted and we all went to the awards ceremony where they won!

Both boys were incredibly close to their granddad Chris, who died from MND in 2021. I'm extremely proud of these two and I know that Grandad Chris would feel the same. Not only for their fundraising for the MND Association but for their continued support with events held in Suffolk, such as a BBQ at someone's house, a football match at Ipswich Wanderers, a coffee morning, or a walk round Bury St Edmunds. They help out at the Kesgrave support group during school holidays, they chat about football (ITFC of course) hand out food, help with the quiz and everyone says what lovely boys.

Thank you Claydon School for putting these two forward for a well-deserved Charity Award.

Sandy Harvey, Very proud Nanny
Volunteer Kesgrave Support Group

Dear editor,

We wanted to share with you all the most wonderful celebrations we had in Sutton Coldfield earlier in the summer, as 101 year old, L/Cpl Harold Jones received a British Empire Medal (BEM) from the King in his birthday honours list.

Harold, who served in WWII, has been fundraising for the MND Association since lockdown, inspired by Sir Tom Moore. Harold has been walking laps of his garden everyday since 2020 and so far has raised over £45,000 and walked more than 43,000 laps of his garden - more than 690 miles.

Harold said after receiving the award: "There's far more people than me behind the BEM. I'm fortunate and well blessed with reasonably good health. I've lost three very good friends with MND.

"At the beginning of Covid I started walking and I dedicated it to them. I thought I might get a thousand walks around the bungalow where I live - and since then I've done 45,370."


Left to right: Amanda Devlin Regional Fundraiser, Lance Corporal Harold Jones BEM and Amanda Bourne, Conference and Events Manager

Well done Harold.

Amanda Bourne, Conference and Events Manager at the MND Association

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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 or search *MND Matters* in your chosen podcast provider.

Episode 34: Behind the curtain with Michael Patrick and Oisín Kearney
Eighteen months after announcing his diagnosis of MND, actor and writer Michael Patrick gives us an insight into his starring role in a special adaptation of Shakespeare's Richard III – in which Richard receives a diagnosis of MND. Alongside friend and creative partner Oisín Kearney, Michael talks about how moments of the play hold up a mirror to his own MND experiences, and the pair give host Domonique a trip down memory lane to relive their past successes, including the award-winning play and BBC3 series, *My Left Nut*.

Episode 33: Q&A with Coronation Street's Dan Brocklebank and Peter Ash
Coronation Street actors Dan and Peter answer your questions in this special episode of MND Matters. Go behind the scenes of Peter's portrayal of Corrie character Paul, who was diagnosed with MND in 2023, and hear more about how Dan's personal connection to the disease influenced playing the role of Paul's husband and carer, Billy.

Episode 32: Caring for someone with MND: Martyn's experiences
In this episode, released during Carers Week in June, Martyn shares his personal experience as an unpaid carer for his wife Anna, who was diagnosed with MND in May 2023. Although Martyn reflects on the challenges he's faced so far, he also highlights the unexpected positives of his caring experiences, which includes spending more time with his young family and becoming involved with campaigning for people with MND.

About us

The Motor Neurone Disease (MND) Association

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

We also campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

As a charity we rely on voluntary donations. Our vision is a world free from MND.

Social media

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

mndassociation

mndassoc

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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 9am to 4pm

mndconnect
0808 802 6262
mndconnect@mndassociation.org

Membership

To receive a regular copy of *Thumb Print*, call 01604 611860 or email membership@mndassociation.org

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

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motor neurone disease
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Play the **The MND Association** Winter Raffle today!

AND HELP MOVE US CLOSER TO A WORLD FREE FROM MND

1st prize: **£5,000**

2nd prize: **£1,000**

3rd prize: **£500**

20 x Runner-Up prizes: **£25**

Thanks to wonderful supporters like you, our last Winter Raffle raised over £120,000 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 Winter Raffle this year!

You can enter by visiting
mnda.raffleentry.org.uk or by calling **0330 002 0342**
Closing date: 19 December 2024 **Draw date: 3 January 2025**

Scan here to enter online

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

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

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

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