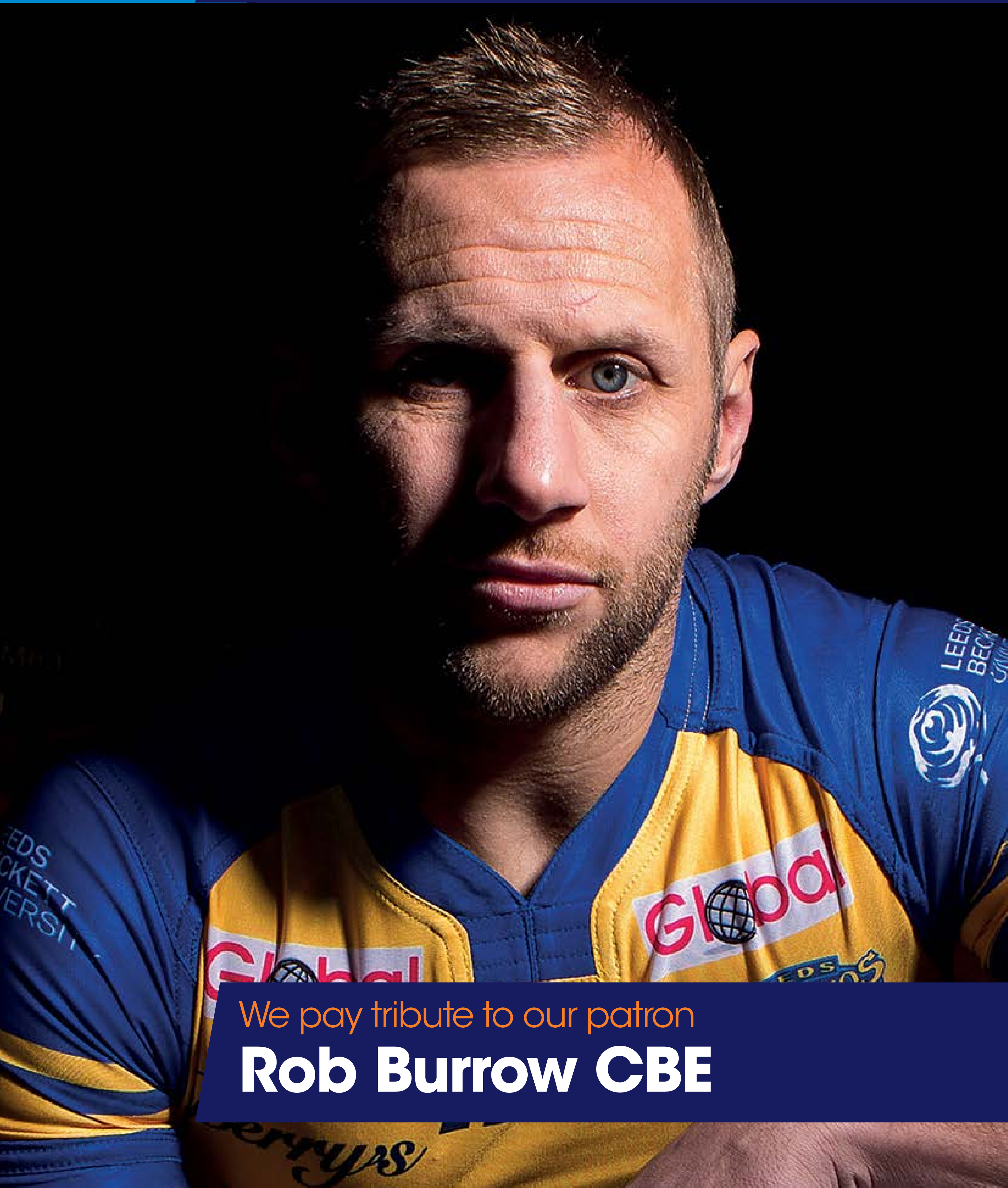
motor neurone disease association
Membership

THUMBPRINT

NEWS FROM THE MND ASSOCIATION COMMUNITY

SUMMER 2024



We pay tribute to our patron

Rob Burrow CBE


Designed & Engineered in Great Britain
ENGINEERING TO ENABLE
4.9/5
★★★★★
Independent Service Rating based on 283 verified reviews

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Marked by political and social action

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Corrie stars open up about their MND storyline

On the cover: Our patron, Rob Burrows CBE, former rugby league player who died of MND in June

mnda
motor neurone disease association

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

Thumb Print is available to read online and as a downloadable pdf at **www.mndassociation.org/thumbprint**

Welcome

from our Chief Executive

"My final message to you is whatever your personal battle be brave and face it. Every single day is precious. Don't waste a moment. In a world full of adversity, we must still dare to dream. Rob Burrow, over and out."

The final poignant words our patron Rob Burrow CBE shared on camera before he died on Sunday 2 June.

Rob was a giant in the rugby league community, thanks to a hugely successful career at Leeds Rhinos. He was a devoted family man, a loyal friend. And he became an inspiration - to thousands of people in the MND community and far beyond by courageously sharing his MND story right until the end.

Here at the Association, we are so incredibly grateful for everything Rob did for, with and on behalf of the MND community. And we are so thankful to each of you who has raised awareness, fundraised or donated to our work in honour of Rob over the last four and a half years. As a result of that, a vital part of Rob's legacy will be the continuation of our research funding programme.

You can find out more about research we fund in our new booklet *Countdown to a Cure*, which is packaged with this issue of *Thumb Print*. This is a bitesize guide to some of the most promising trials underway right now, while shining the spotlight on the outcome of research which is already having a positive impact.

Some of that research was specifically funded by donations from the ice bucket challenge which is, would you believe it, celebrating its 10th anniversary this summer. I know many of you will, like me, remember the global phenomenon that saw people nominating friends and family to have buckets of ice-cold water thrown over them. The MND Association was the key beneficiary in the UK – we received upward of £7 million in donations within a few short weeks. We will be marking that anniversary later in the summer and hope some of you will share your throwback videos on social media as part of that.

Finally, I'd like to say a big thank you to everyone who attended one of our Roadshows this spring, including our Royal Patron HRH The Princess Royal who surprised our guests at the Northern Ireland event! My Executive Leadership Team and I thoroughly enjoyed meeting so many of you, listening to your ideas, thoughts and concerns, and being able to share our plans with you. We hope to be able to repeat these events in the future, visiting different towns and cities and hearing from even more of our community.

In the meantime, my continued thanks for everything you do for people with and affected by MND.

Tanya Curry, *Chief Executive*

Recognising carers on Glo

Each year on 21 June, the MND Association joins with the MND community around the world to mark Global MND Awareness Day.

This year we shone the spotlight on the vital role of MND carers.

We shared the stories of people like Martyn. Last year, Martyn's wife Anna was diagnosed with MND aged just 39. Martyn and Anna have both now given up work with their income dropping around 70% as a result.

Martyn and Anna Barrow with their three daughters

> **Everyone in the house and across our wider family has caring responsibilities.**
>
> Martyn, a carer

Martyn said: "I've worked since I was 14 years old, so it was a challenge giving up work but it was the right thing to do… Everyone in the house and across our wider family has caring responsibilities. We have tried to limit that as a family because Anna doesn't want more carers in her life – she just wants them to be family members.

"I like to think of myself as a problems solver. But, unfortunately, this is a problem that you can't fix."

Research by the MND Association has shown many MND carers dedicate more than 100 hours every week to caring. And very often families face financial hardship as a result. We want the Government to change that. Through our Support MND Carers and MND Guarantee campaigns we've been urging the next UK Government to increase the rate of Carer's Allowance to a level that reflects the real value of unpaid carers.

On Global MND Awareness Day, through striking digital billboards in cities from Cardiff to Manchester and London to Birmingham, information on our website and posts on social media, the Association encouraged people to ask their prospective MPs to pledge support for people affected by MND. That's just the start of us building relationships with the decision-makers who can make a difference to people living with the disease, and those caring for them.

People like Sarah. She joined the MND Association as an Area Support Co-ordinator after her mum Norma died of the disease in 2020. She said: "Nobody tells you how to care for someone, what you need to do or how to do it… we just worked it out as we went along."

Sarah and her sister Suzie with their children

> **Watching someone you love living with MND, you feel powerless. Nobody tells you how to care for someone, what you need to do or how to do it.**
>
> Sarah a carer

Our ambassador *Coronation Street* actor Daniel Brocklebank, whose grandad died from MND, added his voice, through a video shared on social media. He is now on screen playing Billy, the husband and carer of Paul, who Corrie fans watched being diagnosed with MND more than a year ago.

In the evening of Awareness Day, Sky Sports aired a special match played at Leeds Rhinos, in tribute to our patron Rob Burrow. Sky Sports shared information about MND throughout the coverage to raise awareness and encouraged support by sharing a QR code.

One of 82 poster sites around the country

Meanwhile, in London, underground travellers had chance to read Rob's 'dare to dream' quote on the 'All On The Board' whiteboards at stations, and people around the country shared photos of a number of landmarks lit up in Association blue and orange.

bal MND Awareness Day

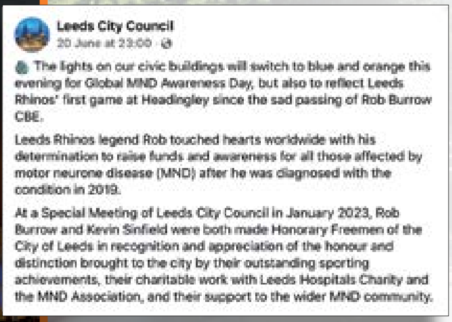
MND Association | Cymru Wales
@mndassocWALES

Today is #GlobalMNDAwarenessDay and like every day, today is the longest day for MND carers as many provide over 100 hours of care a week with little or no financial support

We demand better to #SupportMNDCarers.

Cardiff Castle lit up in orange and blue with members of the local branch

Leeds Civic Hall



Leeds City Council
20 June at 23:00 ·

The lights on our civic buildings will switch to blue and orange this evening for Global MND Awareness Day, but also to reflect Leeds Rhinos' first game at Headingley since the sad passing of Rob Burrow CBE.

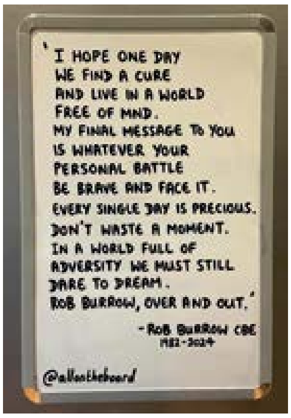
Leeds Rhinos legend Rob touched hearts worldwide with his determination to raise funds and awareness for all those affected by motor neurone disease (MND) after he was diagnosed with the condition in 2019.

At a Special Meeting of Leeds City Council in January 2023, Rob Burrow and Kevin Sinfield were both made Honorary Freemen of the City of Leeds in recognition and appreciation of the honour and distinction brought to the city by their outstanding sporting achievements, their charitable work with Leeds Hospitals Charity and the MND Association, and their support to the wider MND community.

MNDA CARDIFF & VALE
@MNDACARDIFFVALE

Fri 21st June is Global #MND awareness day 💙🧡
@cardiffcastle will be lit up blue & orange to mark the occasion.
Thanks to @cardiffcouncil for making this possible 🙏

Kate Byron, Chair of the Cardiff and Vale of Glamorgan Branch in front of the Cardiff billboard



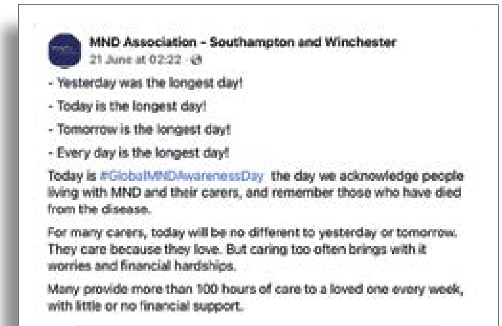
'I HOPE ONE DAY
WE FIND A CURE
AND LIVE IN A WORLD
FREE OF MND.
MY FINAL MESSAGE TO YOU
IS WHATEVER YOUR
PERSONAL BATTLE
BE BRAVE AND FACE IT.
EVERY SINGLE DAY IS PRECIOUS.
DON'T WASTE A MOMENT.
IN A WORLD FULL OF
ADVERSITY WE MUST STILL
DARE TO DREAM.
ROB BURROW, OVER AND OUT.'

-ROB BURROW CBE
1982-2024

@allontheboard

Rob's message from @allontheboard which appeared at stations on the 21 June

Mersey Gateway Bridge lit up for Global MND Awareness Day



MND Association - Southampton and Winchester
21 June at 02:22 ·

- Yesterday was the longest day!
- Today is the longest day!
- Tomorrow is the longest day!
- Every day is the longest day!

Today is #GlobalMNDAwarenessDay the day we acknowledge people living with MND and their carers, and remember those who have died from the disease.

For many carers, today will be no different to yesterday or tomorrow. They care because they love. But caring too often brings with it worries and financial hardships.

Many provide more than 100 hours of care to a loved one every week, with little or no financial support.

20 JUNE

is the longest day.

Research spotlight on Heather Marriott

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

Right now, there are 220 researchers working on MND Association-funded research projects, all with the same goal of creating a world free from MND.

From increasing our understanding of what goes wrong in the body, to finding markers to help speed up diagnosis, to developing effective treatments and improving quality of life, our researchers are at the forefront of MND research.

Dr Heather Marriott was recently awarded one of our new MND pre-fellowship grants. These pre-fellowships, developed in collaboration with MND Scotland and the UK MND Research Institute, bridge the gap between a PhD and a longer term fellowship. The aim is to retain and develop the MND research leaders of the future.

Fresh from completing her PhD under the supervision of three world-leading MND Association-funded researchers, Dr Marriott is now looking to identify groups of people with MND who share similar biological features. She will analyse large amounts of biological information from people with MND to hunt for similarities, such as differences in DNA or activity levels of biological pathways which support motor neurone health and survival.

Explaining the rationale behind her study, Dr Marriott said: "If we know which features are causing or impacting the disease in each group, we can target those more effectively with specific drugs or therapies."

MND is a complex disease so finding groups with shared features could lead to more personalised treatments, which will hopefully improve the chance of finding effective treatments for everyone living with MND.

> **If we know which features are causing or impacting the disease in each group, we can target those more effectively with specific drugs or therapies.**

Dr Marriott's passion for MND research has been influenced by her experiences with neurological diseases. A close family member was diagnosed with progressive supranuclear palsy (PSP), a disease in which brain cells become increasingly damaged over time. This causes problems with balance, movement, vision, speech and swallowing, and there is currently no cure.

This experience has been her motivation to make a difference. She said: "My personal connection ensures that the focus and objectives of my research stay centred on improving outcomes for people with MND."

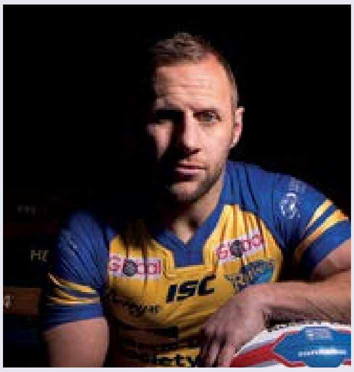
Dr Marriott is keen to involve people affected by MND in her research, and attended last year's MND EnCouRage UK. The event gave her an opportunity to hone her communication skills and present her research to representatives of the MND community. She is now eager to continue to involve people affected by MND through her pre-fellowship.

She said: "Getting to connect closely and communicate my research with people affected by MND is such an exciting aspect of this pre-fellowship, as their experiences and perspectives will inform and shape my research, and I also want to make sure that my research will have a positive impact."

Find out more about Dr Marriott's project and other research we fund on our website: www.mndassociation.org/research/our-research/research-we-fund

(left to right) Dr Ahmad Al-Khleifat, Professor Ammar Al-Chalabi, Dr Heather Marriott, Dr Alfredo Iacoangeli

Remembering Rob Burrow CBE



For four and a half years following his diagnosis with MND, Rob Burrow was a passionate advocate for all those affected by the brutal disease. His commitment to the cause elevated him from a rugby league legend to a face familiar to millions across the country.

His death on Sunday 2 June, prompted an outpouring of love and touching tributes from thousands across the world. Closer to home, a sea of flowers, shirts and cards were laid at Headingley Stadium - the home of his former club Leeds Rhinos – with the stadium later welcoming more than 17,000 fans to a tribute game celebrating Rob's life on Global MND Awareness Day.

A moving documentary, *There's Only One Rob Burrow*, aired on BBC1 the day after Rob's death and contained Rob's last message to the world. "My final message to you is whatever your personal battle be brave and face it. Every single day is precious. Don't waste a moment. In a world full of adversity we must still dare to dream. Rob Burrow, over and out."

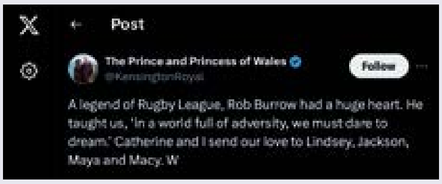
It was in 2001 that Rob begun his impressive rugby league career by making his debut for Leeds Rhinos. Despite being smaller in stature than his teammates and opponents, Rob was one of most successful players in Super League. His playing shirt – number 7 – became iconic.

After noticing changes to his speech, in December 2019 Rob was diagnosed with MND and made the decision to share the news shortly after. From that moment, he used every opportunity to raise awareness of the devastating disease, speaking publicly, undertaking media interviews and opening the doors to TV cameras for two moving BBC documentaries, *My Year With MND* and *Rob Burrow: Living With MND* – both of which were shortlisted for prestigious *National Television Awards*.

Rob remained a consistent and passionate advocate for people with MND – he became the first person to use a communications aid to read a bedtime story on CBeebies. And he joined with others living with MND, MND charities and neurologists to successfully campaign for a £50 million Government investment in targeted MND research. Rob's contribution to rugby league and awareness of MND were recognised in the 2021 New Year's Honours List with an MBE, and that same year Rob accepted the role of patron of the MND Association. Earlier this year, Rob was honoured with a CBE – his medal was presented to him by HRH The Prince of Wales.

In doing so much, Rob inspired support from so many. Thousands of well-wishers, not just in rugby's heartland, but across the country took on fundraising challenges and pledged support inspired by Rob's bravery. In May 2023, Leeds became a sea of blue and orange when 12,000 people took on the inaugural Rob Burrow Leeds Marathon. In the arms of his friend and former Leeds Rhinos captain, Kevin Sinfield CBE, Rob crossed the line of the marathon, and was there to see thousands of others do the same in the 2024 event.

The MND Association is incredibly grateful to Rob and his family for helping to raise awareness of MND, and funds for the Association, by sharing the details of their journey and by inspiring so many people both within the MND community and the wider public.



The Prince and Princess of Wales
@KensingtonRoyal

A legend of Rugby League, Rob Burrow had a huge heart. He taught us, 'In a world full of adversity, we must dare to dream.' Catherine and I send our love to Lindsey, Jackson, Maya and Macy. W

Charlotte Hawkins
@CharlotteHawkins

Just heartbreaking @Rob7Burrow has died after being diagnosed with MND back in 2019. A fellow @mndassoc patron, he was such a beautiful human being who did so much to raise awareness & funds for those with MND. He'll be very much missed. Big love Lindsey, Macy, Maya & Jackson 💔

Dan Walker
@mrdanwalker

He was the little fella who made a massive impact on the pitch and an even bigger one off it.

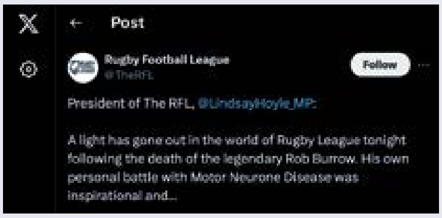
Rob Burrow taught us so much in the way he dealt with his MND diagnosis and inspired millions with his continued determination to help others, despite what he was going through himself. He was a class act.

Sending all my love to Lindsey and their kids, his sisters, his mum and dad and all those who will miss him so much ❤️

The fight goes on.

Stuart Broad
@StuartBroad8

Thinking of Rob Burrow's family at this time. Motor Neurone Disease is so cruel. Rob, his family & community have raised so much awareness & funds that will give us a chance to find a cure. I was with him & Lindsey last week, both incredible people 🧡



Rugby Football League
@TheRFL

President of The RFL, @LindsayHoyle_MP:

A light has gone out in the world of Rugby League tonight following the death of the legendary Rob Burrow. His own personal battle with Motor Neurone Disease was inspirational and...




Regional Roadshows bring

Members across the three nations attended our

Our Regional Roadshows, new for this year, have given members and volunteers an opportunity to hear more about the future direction of the Association and help shape our priorities.

Members and local volunteers were able to share ideas and celebrate successes at the events, and time was given to enable more informal conversations between attendees, Association staff and trustees. Branches and groups were well represented at the Roadshows, held across England, Wales and Northern Ireland. And there was a variety of talks from the MND community on topics such as the positive impact of music therapy, the successful work of our campaign volunteers, and celebrating Pride with the West London Queer Project.

Chief Executive, Tanya Curry and other members of our Executive Leadership Team gave presentations about the future strategy for the Association to help us all achieve our vision of a world free from MND, with a focus on the importance of working together to achieve what the MND community wants and needs.

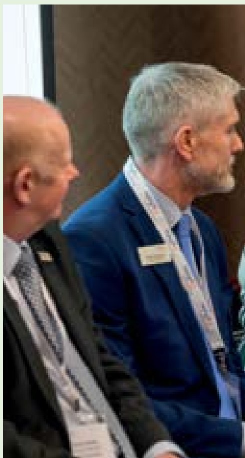
Feedback from the Roadshows will help to shape our priorities with the notes from the various discussions being used as a basis for further planning.

"It has been fantastic to hear so many success stories from across our branches and groups and to be able to share our future strategy with our members. It was important that we gave our members and volunteers the chance to share their thoughts to shape our future strategy and priorities. These events have been the perfect platform to do that.

"I hope all those who attended found the talks by our volunteering community as interesting as I did. The Roadshows have been a fantastic showcase for all the brilliant work that is going on across England, Wales and Northern Ireland."

Matthew Cobble, Head of Volunteering






MND community together

new Regional Roadshow events

Northern Ireland Roadshow receives Royal Patron

The first of our Regional Roadshows took place in April in Country Antrim and included a special visit from our Royal Patron HRH The Princess Royal.

The theme of the Northern Ireland event was 'Supporting the MND Community', celebrating the positive work the Northern Ireland Branch delivers supporting people with MND and their families. Her Royal Highness took part in table sessions, in which attendees discussed key priorities for our work in Northern Ireland going forward, before giving a speech thanking volunteers for their unwavering commitment to supporting local people with MND.

Association visitor, Bernadette McClean said: "I enjoyed the event. It was well organised and I found it to be very informative and friendly. It was a big surprise to see HRH The Princess Royal. We didn't know until we got here that she was going to be in attendance and it's a first for me to have met someone from the royal family. She was very down to earth."


Hugh Thompson ©2024

> **"It was really good to hear about all the research going on. The most important thing I found today was the presentation on voice banking. My wife banked her voice four years ago and her voice is now going.**
>
> **"It was good news to hear that there are now more apps, and free apps for voice banking which will really help us going forwards."**
>
> *Markus Matthews, Vice Chairman of the MND Association for Cardiff and Vale of Glamorgan Branch*



Stonegate smashes £500,000 target

and it's not over yet!

> **Together, via our incredible pub teams and wonderful colleagues in our support teams, we've not only raised funds but also awareness.**

Stonegate Group, the largest pub chain in the UK, has raised an impressive half a million pounds so far to support families affected by MND.

What began as a year-long partnership with the MND Association and MND Scotland in April 2022, is still going strong, and is set to continue until the end of the year.

Stonegate's pub network, and support and operational teams, have thrown themselves firmly behind the cause. Collectively they've taken on a huge number of fundraising activities, from walks and hikes in the South East, conquering 30 miles of the Jurassic Coast, to hosting dinner dances, quizzes, raffles, cycle challenges, canoeing and car washes.

Stonegate Group CEO, David McDowall said: "I'm proud we have raised an incredible £500,000 for the MND Association and MND Scotland. It demonstrates our collective commitment to making a meaningful difference in the lives of those affected by MND. Together, via our incredible pub teams and wonderful colleagues in our support teams, we've not only raised funds but also awareness."

To mark this achievement, Stonegate Group hosted a special cheque presentation at The Fatling in Hornchurch, where the pub's General Manager, Sandy Castle has been a driving force behind their fundraising efforts.

With a summer of fundraising planned to mark Global MND Awareness Day, the team at Stonegate Group shows no sign of slowing down. This very special partnership continues to make a huge difference to our fight against MND.

MND Association representatives accept a cheque for half a million pounds from Stonegate Group

Meet Cindy

Our new Lead Research Nurse

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

Cindy Whitbread, MND Association Research Network Lead

Cindy Whitbread is our new Lead Research Nurse, appointed to develop and lead the MND Association Research Nurse Network.

In February the MND Association announced a £5 million investment to develop a first-of-its-kind co-ordinated network of research nurses across England, Wales and Northern Ireland. The aim of the MND Association Research Nurse Network is to give everyone diagnosed with the disease an opportunity to take part in vital research, as an holistic part of their care.

Cindy brings a wealth of knowledge from more than 20 years working in research nursing, including caring for people with neurodegenerative disorders.

Thumb Print caught up with Cindy to ask about her new role and the vision for developing the Research Nurse Network.

Cindy, why were you drawn to this role?

I've been a lead research nurse for many years supporting neurodegenerative and cognitive health in the community, hospital, clinical research facility settings and, more recently, within the National Institute for Health and Care Research co-ordinating centre. My focus has always remained person-centred with an emphasis on equity to research opportunities. The values of the Association, the drive to improve care and treatments for people living with MND is absolutely inspiring and I want to be part of that journey.

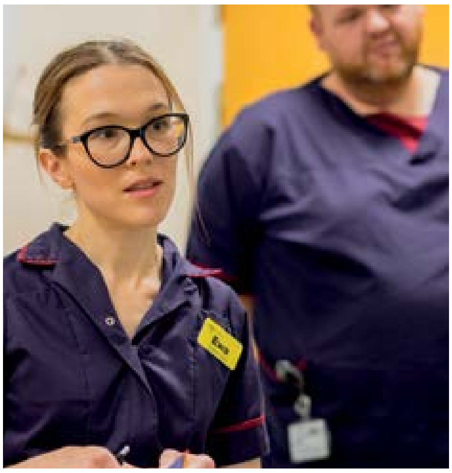
What impact will these nurses have?

MND Association-funded research nurses will help people with MND navigate the research trial process – providing information about current MND clinical research, identifying trials they are eligible for, explaining what's involved, and supporting with their ongoing involvement.

Ultimately, I want everyone diagnosed with MND to have the opportunity to take part in a trial if, they want to. With trials come hope – people living with MND need that. It would make such a difference if when someone is given a diagnosis of MND, they're told about a trial they can go on that might improve their life expectancy or reduce their symptoms.

What can we expect over the coming months?

The research nurse role, responsibilities and locations are currently being mapped to work out where the first nurses will be located. They will work closely with the MND Association Care Centre Network and other specialist centres. Planning for the recruitment and implementation of the roles is underway and it's anticipated the first MND Association Research Nurses will be recruited by the end of November. We want to find nurses with a real passion for making a difference to both those living with the condition, but also to pushing forward research.



Research nurse at Queen Elizabeth Care Centre

We will share more about the development of this programme in future editions of *Thumb Print*.

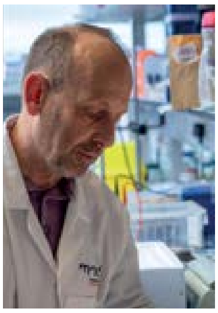
Sam Perkins meets research team he's helping to fund

BBC Presenter Natalie Jackson speaking to Sam for East Midlands Today

The research team at the University of Nottingham, led by Professor Robert Layfield, welcomed Sam Perkins, co-founder and trustee of Stand Against MND giving them a chance to demonstrate the work his significant donations are funding.

The team is currently carrying out research to better understand MND mechanisms – the biochemical processes that go wrong – in order to speed up the race to find new treatments. In this project, scientists are targeting specialised cells, called astrocytes, that help protect and support motor neurones. In MND, astrocytes can become less effective at protecting motor neurones from damage. By blocking a naturally occurring molecule, it is hoped the protective function of astrocytes will be restored.

This project is part of Stand Against MND's Research Partnership with the University of Nottingham, funded in collaboration with the MND Association. Sam is keen to support early career researchers and provide funding to help develop the next generation of MND research leaders.



Professor Rob Layfield

Hannah Bailey, PhD student researcher

Professor Rob Layfield said: "This generous support from Sam Perkins at Stand Against MND is so important as it not only helps us build the critical mass to ensure that the University of Nottingham continues to be part of the international effort to beat MND, but it also ensures that the most talented young scientists have the opportunity to start a career in MND research. Sam reminds us why we do what we do".

The Studentship at the University of Nottingham has been named after Sam's charity Stand Against MND, honouring his drive, determination and dedication to help researchers make those important discoveries which will take us closer to effective therapies and eventually a cure.

The MND Association are incredibly grateful to Sam and Stand Against MND for joining us in funding this important research.

Morrisons Foundation grant for communication aids

Communication aids can make a huge difference to people with MND who have lost their ability to speak. The MND Association loans communication aids to help people with MND whose speech has been affected.

With demand for this service continuing to increase, we approached the Morrisons Foundation to help fund some new Lightwriters. Lightwriters are text-to-speech devices – people use the keyboard to type text which the Lightwriter than 'reads out'. With proper maintenance, a Lightwriter can last for many years.

The Foundation provided a grant of £8,400 for the purchase of four new SL50 Lightwriters that will be loaned by the MND Association to people with MND.

David Scott, Morrisons Foundation Trustee said: "I'm very proud we've been able to offer this grant to substantially improve the lives of people living with MND. The ability to communicate effectively thanks to this innovative piece of equipment really will make a massive difference to so many people affected by the disease and their families for many years to come."

Pauline Matheson-Marks, Head of National Support Services said: "Over 80% of people living with MND will experience changes to their speech, so specialist communication aids can make a huge difference to the daily life of many people with the disease. This equipment can be expensive, but our communication aids service is there for anyone who needs that support. We are incredibly grateful to the Morrisons Foundation for giving us the opportunity to increase the number of communication aids equipment we have available and know these will be so valued by the members of our community who need it."

Controlled trial to evaluate if diet can slow MND

A trial to investigate the effects of good nutrition on people with MND is recruiting participants.

Researchers at Sheffield Institute for Translational Neuroscience (SITraN), supported by the MND Association, have developed a tool which aims to help get nutrition right for each person with MND. The tool, called OptiCALS, helps people with MND track their calorie intake and sets personalised calorie goals.

Several studies have suggested that increasing calorie intake can potentially lead to slower disease progression and help with weight gain. But further research is needed to confirm what benefit, if any, a personalised diet may offer people living with MND.

The clinical trial will compare OptiCALS with usual care and assess whether using it helps to slow disease progression.

Participants allocated to use the OptiCALS tool will be encouraged to follow a diet that meets an individualised calorie target from food, rather than relying on nutritional supplements.

The calorie target will be informed by a specific equation which takes into account their weight and whether they are losing or gaining weight, and a prediction of how much energy they are using on a daily basis.

By logging onto the OptiCALS online portal people will be able to monitor their calorie intake. If they are falling short, the portal will offer advice on the kind of foods they could eat to boost their calorie intake. It will take into account any difficulties they may have, with swallowing or chewing for instance, so providing tailored support.

The body uses energy in three ways:

70% is used when the body is at rest

20% is used during exercise

10% is used to break down food

Previous research has found that many people with MND experience weight loss, and it is thought that around 20 people out of 100 with MND will have lost 10% of their weight by the time they are diagnosed.

Some of this weight loss may be due to a person experiencing difficulties with chewing and swallowing because of increasing muscle weakness or a lack of appetite. It has also been reported that people with MND use more energy, known as hypermetabolism, which often leads to weight loss as more energy is being used than is being taken in. If you, or someone you are caring for is struggling with eating and drinking, our guide *Eating and drinking with MND* contains information, tips and easy-swallow recipes.

Please contact MND Connect on 0808 8026262 or email mndconnect@mndassociation.org for a copy.

OptiCALS is currently recruiting across the UK. Find out how to take part on our website: www.mndassociation.org/research/get-involved-in-research/take-part-in-research/opticals

Pushing themselves to the limit for MND

TOYOTA GB is aiming to raise £300,000 for the MND Association this year in memory a much-loved friend and colleague who died from MND.

Fundraisers at Toyota GB, and its entities, Toyota Financial Services, Toyota Insurance Services and KINTO UK, will be taking part in a number of challenges over the coming months to support the Association's work.

Cyclists from Toyota GB stopped off at our offices in Northampton during their 420-mile ride from Portsmouth to Newcastle

As well as a 420-mile cycle ride from Portsmouth to Newcastle in June, a team of directors will be taking part in a 100km walk in September. Since launching its charity partnership in 2021, Toyota GB has raised £250,000, pushing forward the Association's work in key areas including the provision of support grants, care for people living with MND and their families and research.

Ahead of the charity cycle, Scott Thompson, Toyota (GB) President and Managing Director, said: "I'd like to thank all our colleagues who will be pushing themselves to the limit in undertaking this tough challenge, and those participating in our other fundraising activities this year. We want to go further than any other corporate partner of the MND Association in raising £300,000 this year, to help fund the valuable work carried out by the charity."

Chief Executive of the MND Association, Tanya Curry said: "We couldn't be more grateful to our partners at Toyota who have done so much over the past three years to support the Association.

"Their extraordinary efforts help us to go even further in the fight against MND, enabling us to fund life-changing care and support for people who are living with and affected by this devastating disease, while accelerating ground-breaking research into the causes of MND."

Marathon season for #TeamMND

2024 has proved a busy marathon season for #TeamMND. During April and May, 1,174 runners took part in marathons across the UK and abroad, clocking up more than 30,500 miles between them.

London Marathon

After months of training and fundraising, our London Marathon team of 215 runners assembled in Greenwich for the race across the capital to the finish line on the Mall.

Sam Perkins and his team during the marathon

Among them was Adam Powell. He was inspired to run in support of the Association having seen the impact MND had on his close friend Eoin Egan (also see page 35), and Eoin's family. Adam completed the marathon in 4 hours 51 minutes and raised an amazing £10,000.

Sam Perkins was on the start line for the second consecutive year. Sam, who is living with MND (also see page 12), and his team were given another opportunity to take part after a malfunction with his wheelchair meant he couldn't complete the race in 2023.

Adam Powell

Ini his blog Sam reflected on crossing the finish line. "I am emotionally spent and I'm not alone. We collapse together amongst waves of relief, gratitude, pride and joy. In the most authentic of team efforts.... Business Finished."

Neil Taylor secured a sought-after ballot place before he was diagnosed with MND in January. Despite his symptoms, Neil was determined to complete the race along with his daughter Jodie, who was given a guide place to run alongside him.

Our patron Charlotte Hawkins supported our team of runners which included her brother Richard. She said: "It's amazing to be here at the post marathon celebration cheering on everyone who has run in support of this amazing cause. There is such a brilliant atmosphere! I want to say a massive thank you to everyone who has run or supported today. Every penny raised really does make a difference."

Brighton Marathon

Just a week later, the Fundraising team were at the south coast, seaside city of Brighton, ready to support a 62-strong team of runners. Among those on the starting line was Lauren Petchell, who signed up for the Brighton Marathon after not securing a place in the London Marathon.

Lauren said: "The charity is very close to my heart. My dad was diagnosed with MND in 2015 and the MND Association has been so helpful in supporting him and our family, so I wanted to do something to help raise awareness and funds for the charity.

The experience was great. The motivational emails during the lead up really helped, and on the day the team were so friendly and encouraging when they spotted me on the course." To date, our Brighton Marathon team's fundraising has topped £52,000.

Lauren and her dad

June Allingan 80, who completed her 12th marathon

Rob Burrow Leeds Marathon

The MND community united for the Rob Burrow Leeds Marathon on Sunday 14 May, just three weeks before Rob, our patron, sadly died.

The 739 #TeamMND runners tackling the 26.2 mile route were joined by more than 300 others running the Leeds Half Marathon. Both events started and finished at AMT Headingley Rugby Stadium, where rugby legends Rob and Kevin Sinfield played with the Leeds Rhinos.

Kevin, an MND Association patron, took part in this second running of the event. He said: "As people know, I am a very proud supporter and last year was incredible but today is equally as special. I can't thank people enough including the volunteers and all those that have helped create this today. Every single runner has put hard work in and has made it such a special day."

For June Allingan, who is 80 years old, the Rob Burrow Leeds Marathon was her 12th marathon. She said: "The MND Association was chosen as our Wives Group Charity for this year. I started running marathons when I was 60 and have now completed 12. I think this was the toughest one so far, very hilly and of course the day was very hot. However, I finished the race as first female in my age group 80 years+ in a time of 6hrs 21mins. The support on the day was outstanding and lots of the locals kept us supplied with jelly babies, drinks and, more importantly, hosepipe showers to keep us cool. A great day and a great charity to support."

Manchester Marathon

This year 83 people – our most ever – joined us for the Manchester Marathon. Rob Whitby took part in memory of his uncle who died just a few months before the race.

Rob said: "After a relatively short battle with MND, his mum asked if I'd help raise awareness. I was already committed to running the marathon, so I thought what better way?

"The marathon was tough, but I got a new personal best, beating my previous time by over 40 mins. Seeing and hearing the cheers from the team at Stretford was a real help in the final slog towards the finish line!"

The cheers were thanks to volunteers from our Manchester and District Branch, who attended the event once again to support our runners. Together, the Manchester Marathon team raised more than £100,000.

Rob Whitby pictured with marathon mascots Manny and Chester bees

Enhancing access to information for health and social care professionals

We have a wide range of information resources available to support health and social care professionals, and the people living with MND they work with.

As our provision has expanded over the years, it can be challenging for professionals to find exactly what they are looking for. They may be looking for information for themselves, their colleagues, as well as the people with MND, carers and families they are supporting.

We currently have almost 200 resources that may be of interest to them, in a wide range of formats such as webinar recordings, infographics, videos, booklets and much more.

To streamline this process, we have launched a new information finder tool for professionals on our website. It enables professionals to easily find all our resources on a specific topic or for their profession. The results will include links to all of our resources for them, and for the people with or affected by MND they are supporting.

They can select multiple topics at once if they wish, and they can then send those via email, either to someone else or themselves.

Visit www.mndassociation.org/professionals/information-finder to view the tool.

Land's End to John O'Groats challenge raises money and awareness

Two friends from Teesside completed an epic cycling challenge to raise money for MND charities in memory of their friend who died from MND.

Chris Hooker and Joe Johnson set out from Land's End on their bikes and cycled to John O'Groats to raise money and awareness for the MND Association and My Name'5 Doddie Foundation.

> **This was a massive challenge but one Chris and Joe were willing to undertake to help those suffering from MND.**

The pair cycled around 1,000 miles over the Easter weekend, cheered on by friends and family and supported by the rest of 'Team Jax' including Chris's son Seb, 11 and daughter Maya, 4.

The challenge was the culmination of a year of fundraising events raising over £10,000 inspired by Jax Bradburn. Jax died from MND in June but the team intend to continue fundraising in her honour, as Team Jax member Elaine Hooker explains: "This was a massive challenge but one Chris and Joe were willing to undertake to help those suffering from MND. They, and their carers, have massive challenges every day, as we saw first-hand with Jax, but her determination and inspiration lay behind our motivation to do our best."

Friends Chris Hooker and Joe Johnson at the start point of their challenge

Swim 6km in May

1,200 take the plunge

Over 1,200 people took part in our challenge to swim 6km in May. Together they've raised over £171,000 to support families affected by MND and fund vital research.

Natalie Lynn, who was diagnosed with MND in February aged just 29, joined the challenge to help others affected by the disease. Natalie said: "I started swimming when I was four years old. My mum was a swimming instructor and a lifeguard on Blyth Beach in Northumberland. Swimming has always been a part of my life.

"Over the years I have supported many charities. I now want to support everyone who has had a diagnosis of MND or who is caring for someone with this horrendous condition. Every little bit helps to provide support and fund medical trials that are going to give us all hope."

Natalie's mum Sue Shaw joined the challenge to support her daughter. Sue said: "All Natalie's life aspirations, hopes, dreams were instantly taken away with the diagnosis. I teach swimming for a living and the water has always been a happy place for Natalie and I. Natalie loved the water from a young age, becoming a competitive club swimmer and a wonderful teacher. We used to swim together all the time, so when Natalie heard of the challenge she loved that I had signed up."

Natalie is very proud of her mum for taking part. She said: "Mum never takes time out for herself. This challenge is the perfect reason to get her back in the pool, completing the pastime she loves whilst helping others."

Natalie completed the challenge while on holiday in Florida. And she wasn't the only participant to take their challenge international - a number of swimmers put in their lengths in exotic destinations including Egypt, Tunisia and Antigua.

Swimmers logged their sessions to keep track of the distance completed to tot up to 6,000 metres or six kilometres. As a team, swimmers logged an incredible 3,747 kilometres.

Natalie Lynn who is living with MND pictured left, with her mum Sue Shaw who took part in the challenge

Some participants went over and above the target with a few swimming the distance of the English Channel (34km), and some swimming 6km every single day.

Find out more about our forthcoming Facebook challenges by visiting www.mndassociation.org/facebookchallenges

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Chair's Message

In this issue of *Thumb Print* you can read a tribute to our patron Rob Burrow CBE, who sadly died early in June, four and a half years after being diagnosed with MND.

I had the pleasure of meeting Rob several times and was touched by his generosity of spirit, his courage and that fabulous smile of his. He achieved so much on the rugby pitch and, latterly, on behalf of the MND community. He will be missed.

Our Roadshows this spring have been a brilliant reminder for me of the passion and drive we are so fortunate to have in the MND community. Getting chance to sit and listen and share with people who have MND and who have been affected by it – some of whom have been involved in our community for many years – has given me, our Board of Trustees and our Executive Leadership Team some really valuable insights as we work together to build and launch our new Association strategy. We've heard how much you want the hope that research gives. Equally we've listened to you talk about the importance of now – of the support you need today and tomorrow. That's the balance we're seeking and we look forward to checking in with you all over the coming months and years to ensure we're getting it right. At the end of June we held our 39th Annual General Meeting. We are pleased to welcome to the Board of Trustees, Liz Ellis, Ed Cooke, Michael Hope and Alan Graham.

As I write this, we've just marked Global MND Awareness Day. Thank you to everyone who got involved. The day marks the start of another busy summer with research events, fundraising initiatives and more awareness campaigns planned and, of course, the run up to the 10th anniversary of the Ice Bucket Challenge – such a wonderful array of activity all carrying us towards our vision of a world free from MND.

Dr Usman Khan

In memory of Caroline

Anthony Goddard shares a heartwarming testimony about the life of his much-loved wife

My wife Caroline was a beautiful person – her outer beauty was matched by an inner beauty – which was evident to all who knew her well. She was as colourful in dress as she was in decorating our home.

She started working life as an interior designer but as children came along, adapted to become a Montessori teacher, starting two schools, one in Germany and one in the North East of England, before becoming a special educational needs teacher. When I was appointed Head of a boys' boarding prep school in Yorkshire, Caroline supported me 100% in a 24/7 role.

Her first love was our family – three children born in the space of four years - she was a brilliant mother and grandmother. Creating beautiful homes was one of her greatest gifts and during our married life she completed that task eight times. Caroline was very practical, enjoying upholstery, making soft furnishings and painting furniture. She also loved sailing, so when we retired and moved to her childhood home on Chichester Harbour, she was able to sail her Lymington River Scow.

In November 2020, Caroline was diagnosed with MND. She'd had a few uncharacteristic falls, was finding it difficult to lift her left foot, and could no longer run upstairs which had been her habit.

Almost from day one of her diagnosis, she was contacted by her local MND Association representative, who guided her through an application for Disability Living Allowance providing reassurance and ongoing support. Regular contact from the Association, together with the extensive support of an amazing network of NHS specialists, meant Caroline had all the medical, emotional and mechanical support she needed as she gradually lost the movement of all her limbs, the ability to eat and the ability to speak.

Main picture, left to right: Sam Goddard, Chloe Kipling, Caroline Goddard and Henrietta Metters. Insert: Caroline and husband Anthony

During her illness and following her death, the fundraising efforts of family and friends have been extraordinary – a total of nearly £150,000 has been raised for MND related charities, including around £125,000 for the MND Association and around £25,000 for the Euan MacDonald Centre. These efforts included a sponsored swim off the coast of the island of Elba, a sponsored marathon, donations by our daughter's employer, medical charities linked to our family, funds raised by the sailing club and at various memorial services.

Our family will continue to support the MND Association, mainly through donations, and will always be grateful for the safety net that was provided during such a difficult period. As a Christian, Caroline saw the love and practical help she received during her MND journey as evidence of God's love for her and, despite her illness, she remained more concerned for others than for herself until her death in July last year.

Introducing the new Campaigns Newsletter

In April, we launched our new *Campaigns Newsletter* which goes out every month to our wonderful supporters and campaigners like you.

The e-newsletter brings you all the news from the Campaigns, Policy and Public Affairs Team, from new campaigns and updates on our behind-the-scenes work for people affected by MND, to news the work of our All-Party Parliamentary Group on MND.

Most importantly, we will let you know how you can get involved to make a positive difference for everyone affected by MND – now and in the future.

If you would like to hear more about the work we do with politicians and decision-makers, join the Campaign Network today to receive our newsletter! You can sign up on our website www.mndassociation.org/campaign-network or scan the QR code.

MND Guarantee Campaign aimed at MPs and candidates

PROMISE 4
WE WON'T REST UNTIL
YOU ARE HEARD

As we enter a critical period for MND research, and with recent cost of living increases and the health and social care system under strain, it's more important than ever the voices of people affected by MND are heard in the new Parliament.

Our campaign *MND Guarantee*, launched in the run up to the General Election aims to make sure that improving the lives of people living with MND is high on the political agenda.

With the help of many of you around the country, we asked candidates standing to be MPs to sign the *MND Guarantee*, pledging to champion the needs of people with MND if elected.

At the time of writing in the middle of June, we have secured pledges of support from over 100 candidates from all parties, and expect more. One of our supporters, Jessica, explains why this campaign is important to her: "Engaging with MPs and candidates is a way for your actions to have a potentially really big impact on things that affect people going through MND in the future.

> **"If we can convince MPs, it could help lead to policy changes across a range of areas that could make a real difference to people with MND. Some of this helps our loved ones now, and some of it will help those who get MND in the future.**

"If we can convince MPs, it could help lead to policy changes across a range of areas that could make a real difference to people with MND. Some of this helps our loved ones now, and some of it will help those who get MND in the future.

"I am driven by not wanting anyone to ever go through some of the things my family has been through. When someone you love goes through MND, you feel so powerless, fighting against the care system, the health system, the housing and transport sectors etc – it's immensely frustrating. Engaging in campaigning is the opposite of that – it empowers you to help change things, potentially at a countrywide level."

Now that the election is over, our aim is to help our new MPs understand more about MND and – as Jessica says – become strong advocates for our cause, both locally and in Parliament.

To find out more about how you can help with this next stage of the *MND Guarantee* campaign, please see www.mndassociation.org/mndguarantee. Or contact us on campaigns@mndassociation.org and 0203 875 8910.

Coronation Street stars talk to *Thumb*

One year on from Paul's diagnosis

> There have been several times where what they've written has brought back very visceral memories. It was when Paul broke the news to the rest of the family, and they were all sitting in our little living room. He got up to leave, which was so reminiscent of what I'd seen with my grandfather.

Actor Peter Ash as Coronation Street's Paul on set

"Just this week, all he did was turn his head and I cried," says Daniel Brocklebank, referring to his *Coronation Street* co-star Peter Ash.

The pair, who play couple Billy Mayhew (Daniel) and Paul Foreman (Peter), spoke to *Thumb Print* a year on from Paul's diagnosis of MND on the soap.

Paul's journey with the disease has been shared in intimate detail on screen, highlighting the impact of MND on him, his family and friends. Peter, who first appeared on the show in 2018, admitted getting to grips with the physicality required in the role was "tricky".

He said: "It is being aware of what parts of the body aren't working and we have started with Paul's speech deterioration as well, which is another layer of complexity on top.

"It's been written brilliantly and researched amazingly. There was the visit to the lake where Paul dares Billy to go skinny dipping with him – that was an amazing day, so much fun to do.

"The production team have done well at picking out these truthful, funny moments, and we have had some of the best responses from people living with MND.

"I've always said it's a double-edged sword. I will be so sad to leave but wouldn't have been given these beautiful scenes to perform. I do feel honoured because it is amazing to raise awareness and money for the cause."

Peter Ash who plays Paul Foreman diagnosed with MND

Daniel has his reasons for finding the subject matter so impactful after his grandfather, Ron, died in 2001 from MND.

"There have been several times where what they've written has brought back very visceral memories," he said.

"It was when Paul broke the news to the rest of the family, and they were all sitting in our little living room. He got up to leave, which was so reminiscent of what I'd seen with my grandfather.

"It's been cathartic to revisit it, knowing how much attention we're bringing to the illness. Strangely, it's been nice to commemorate my grandfather."

Given Paul's diagnosis, there will be an inevitable exit for Peter on the show which Daniel has described as 'bittersweet.'

He continued: "I adore him and love working with him and despite the gravity of some of the scenes we shoot, we laugh every day.

"It is a joy to turn up to work. I'm losing Pete and Billy is losing Paul. Pete will still be on the end of the phone, and we can

Wedding day smiles from characters Billy and Paul

go for a pint, but we've lived this storyline in real time.

"Six years we've been working together every day. When Billy is crying, they are my tears as seeing the physical decline is quite hard.

"Pete's attention to detail has been amazing, and everybody is invested in this performance. He's doing an incredible job."

Daniel said he hopes the storyline will 'get conversations going among viewers' because they are 'in people's living rooms for three hours a week.'

The storyline has provided a platform for the Association's ongoing awareness campaign, *The Love Inside*, which features television adverts playing during the breaks in *Coronation Street*.

And Daniel and Peter have become tremendous ambassadors for the charity, attending several MND fundraising events and raising money for the Association.

Daniel said: "The MND community is one you do not want to be a part of. But once you are, it is such a beautiful group of people. It's a privilege.

"Nobody wants to lose a loved one or family member to such a nasty, vile, cruel illness but the community is joyful.

"The events are always fun and filled with such positivity and hope. With each one we attend, there is a little glimmer you're one day closer to finding something that will slow this down or eradicate it.

> **“**
>
> **The MND community is one you do not want to be a part of. But once you are, it is such a beautiful group of people. It's a privilege.**

"We get to go to these amazing do's, with amazing people, raise nice chunks of cash, wake up slightly rough the next day. We've got another five or six at least booked."

Peter adds: "It's such a horrific thing, isn't it? Your heart just goes out to everyone and the families living it.

"We can leave this story at the door whereas people living with it can't do that. It's important to disconnect and unwind from it and that might take a couple of beers."

On the topic of how they manage the heavy subject matter, Daniel said: "Pete and I had a meeting with the director about an upcoming episode and all he did was tell us the brief outline of the story and we both burst into tears at the table.

"We hadn't even read the bloody scripts, but we have been existing in this high emotional state now for quite a while.

"You come home, you burst into tears reading it, then you cry all day filming it, and then you cry when it's on. It is emotional and draining but feels like an important story to tell."

It has been an amazing journey for the duo, with episodes in May showing Paul's MND support group lose their meeting venue due to funding cuts and raising money in brilliant style – organising an all-night 'karaokethon'."

Peter added: "It's going to be strange leaving Paul as I have never inhabited a character for this long. I'm grieving him in a weird kind of way.

"As the clock's ticking and it's getting closer, I feel a bit more apprehensive but yeah, I'm excited to see what's next."

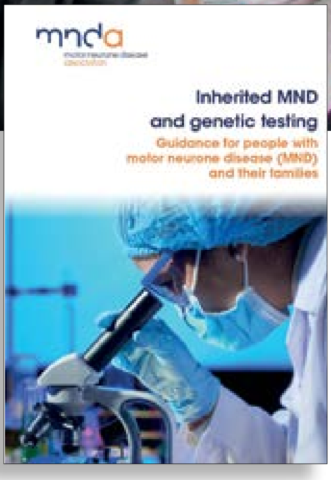
The screen couple sharing a tender moment

Genetic counselling and MND

Team share their views

PROMISE 3
WE WON'T REST UNTIL
EVERY DAY COUNTS

Left to right: Sophie Davies, genetic counsellor, Laura Furness specialist registrar, Georgia Brown genetic counsellor, Rhona MacLeod consultant genetic counsellor, Ellie Nicholson principal genetic counsellor, Amy Dillon genetic counsellor, Kirsten Chalk genetic counsellor from the Manchester Centre for Genomic Medicine



mnda
motor neurone disease association

Inherited MND
and genetic testing
Guidance for people with
motor neurone disease (MND)
and their families

For people with a family history of MND, it may be possible for genetic testing to find out if they carry a changed gene linked to MND. It is vital that alongside these tests, genetic counselling is offered to support the person through the process, and once the results are ready. Here genetic counsellors from the Manchester Centre for Genomic Medicine, share their expertise.

What is genetic counselling in MND?

Genetic counselling is a conversation with an expert that provides tailored information and support, following a genetic diagnosis in a family. When a person has been diagnosed with MND and a known gene change is found, relatives may wish to see a genetic counsellor to explore what this means and their options.

Why does someone usually want to see a genetic counsellor?

There are many reasons, from understanding a family history of MND and how to explain this to relatives, to finding out about research opportunities.

I recently saw a young woman with a family history of MND. She wanted to know what her chances were of getting the disease. Genetic counselling allows people to explore options. Sometimes a person wants to know what is involved in having a predictive test and how other people cope. Some people want to see a genetic counsellor as they are planning to start a family and want to learn about the options available.

My relative has a gene change linked to MND, do I have to be tested too?

No, most people at risk of inheriting a gene change linked to MND choose not to be tested. This may change in the future as more trials and treatments become available. However, it is an option.

If you don't have MND, but a relative does and a gene change has been identified, you can have a 'pre-symptomatic' or 'predictive' test. You would be offered several sessions with a genetic counsellor to discuss the pros and cons, and possible outcomes.

When learning about a genetic diagnosis in a family, relatives often have an immediate response to seek a genetic test themselves. Over time this can change. It's a very personal decision and what is right for one person, may not be for the next, even within the same family. A common reason for wanting a genetic test is to take away uncertainty for the future. However, a genetic result doesn't always provide this.

There is a lot to consider before having a genetic test, so we have several appointments to ensure people are as prepared as possible. This helps us to discuss how we can best support people through the process.

How do I access genetic counselling?

Ask your GP to refer you to your nearest genetics centre.

Is there any information I can read?

See *Inherited MND and genetic testing*, a new MND Association booklet.

A reader affected by MND said: "It can help you gain knowledge and think through the implications at your own speed, so you're better equipped to decide if you want to pursue the topic."

Download the booklet at www.mndassociation.org/inheritedmnd. Order a printed copy from the MND Connect helpline on 0808 802 6262 or by email: mndconnect@mndassociation.org

“A fascinating day of wisdom and care”

Researchers talk about their work

The Francis Crick Institute opened its doors to 40 MND Association supporters, who heard first-hand from leading researchers about their work.

The Association’s legacy events showcase the importance of gifts in Wills in the fight against MND. Making up one third of the Association’s income, they have a huge impact on the research and care we can commit to funding in the future.

Supporters were given an insight into the 14 research projects funded by the Association at University College London (UCL) and the Francis Crick Institute, thanks in part, to the generosity of those who have already left a gift in their Will.

For supporter Anna Mason, the enthusiasm and optimism of the experts researching MND was her favourite part of the day. She said: “It gave me such hope for the future.” While for Stella Ecclestor, her key takeaway was ‘the positive outcomes of the research being carried out for future sufferers and how far support has come. Excellent presentations’.


Attendees at the legacy research event

Attendees were offered a special tour of the Institute, with a sneak peek into the labs. Attendee Julian Howard said: “At last, some optimism to manage and treat the grimmest of diseases... the tour of this outstanding facility... hugely impressive. Thank you so much for arranging this visit.”

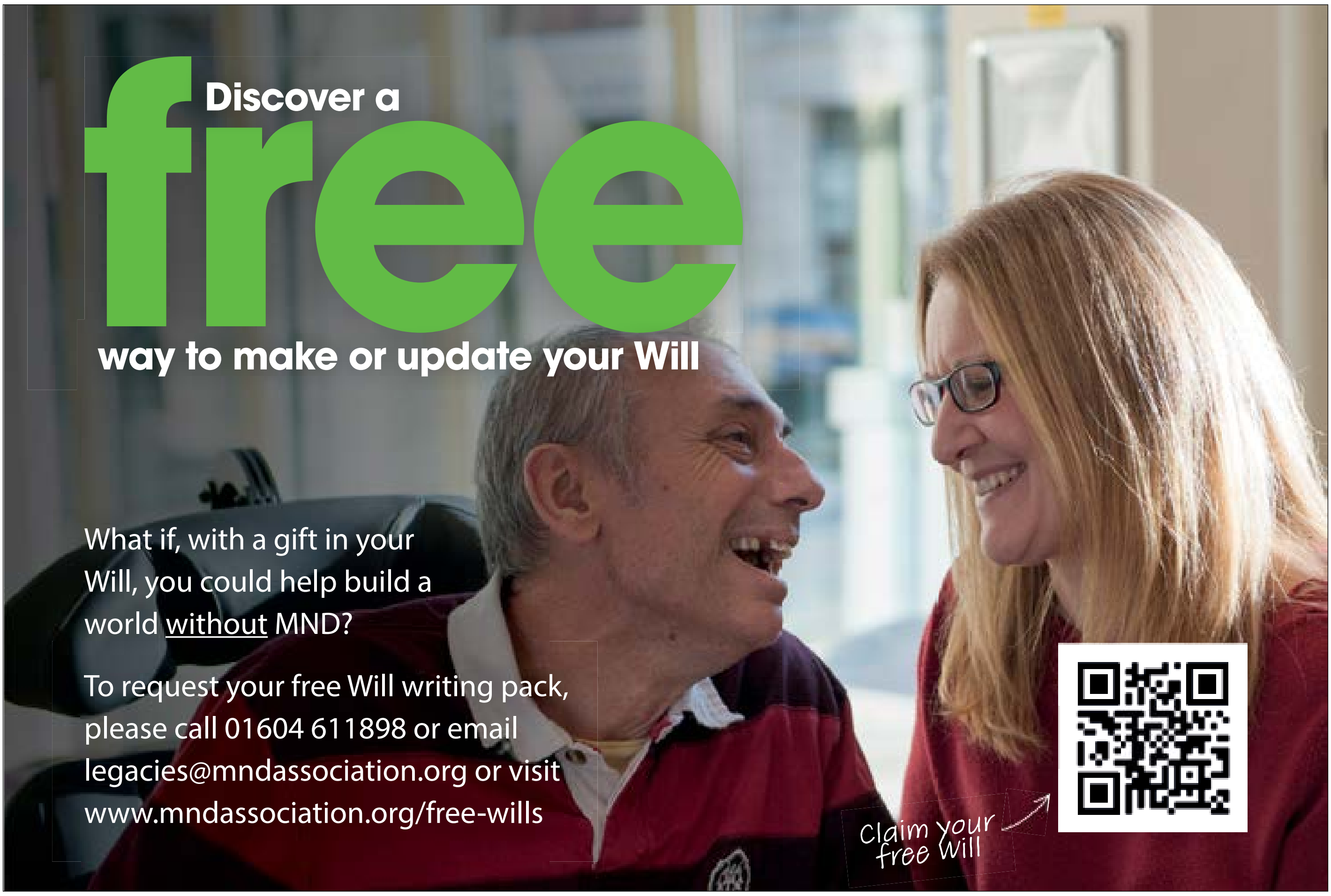
Future legacy events

If you would like to attend a future legacy event to see the impact of your support in action, here are our upcoming events:

Thursday 12 September 2024
Virtual Legacy Event
No matter where you are in the country, join us online to hear about the latest updates in MND care and research. Ask your questions directly to MND staff and researchers.

Thursday 31 October 2024
Sheffield
The Sheffield Institute of Translational Neuroscience (SITraN) opens its doors to our supporters for another inspirational day. This event includes a tour of the laboratories.

For more information visit www.mndassociation.org/wills



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

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

"Some days everything hurts but I try to focus on the good."

YOUR STORIES

Nickie Davies, 47, was diagnosed with MND in July 2023 after noticing symptoms for 18 months. A keen horse rider and mother to daughter Ellie, Nickie uses the communication app on her phone to tell us about her MND, life with her horses and the incredible support of her family.

The first symptom was yawning excessively. I went to my GP, and they sent me to an ear, nose and throat specialist. I was told I had functional neurological disorder.

My symptoms continued, and my voice was becoming slurred by summer 2022. It was hard and scary. I didn't know what it was. I always wondered if it could be an MND, but I was told by two neurologists it wasn't. When I was told it was MND, my world fell apart.

My experience of being told I had MND was lacking any sort of empathy. It was like 'yeah, it's MND, have you got any questions?' Then they want you to see all sorts of people and I feel this is too much on the day, well it was for me, I just wanted to get out of there!


Nickie and her horse Maisie

Looking after the horses and the stables gives me a purpose, and I wouldn't be without them. I used to work 24-hour shifts, so I need to keep busy. Now, I pace myself and only do what I can. I have a wonderful family and friends and partner who help me.

Ellie is only 16 and she has been wonderful. She understands my speech and she has stepped outside her comfort zone and talks for me when I can't. We go away a lot still, and I'm so proud of the young lady she has become. My partner has been amazing and treats me like I'm still the same. We have always had humour which we still carry on with. Only thing is with MND, I can't stop laughing. If I start, I can't stop.

The MND Association has been wonderful and got me an iPad. I have the predictive app that has a voice used from my voice notes, but it doesn't sound like me as I didn't have enough minutes. I would suggest to others to use voice notes in case they're ever needed. There is also an option on iPhone to voicebank.

It's very hard at first to process everything but, after a while, I would advise to keep positive and have hope, and live each day to the fullest. Everyone is different with the journey and it's key not to compare yourself with others. I mask it well as some days everything hurts but I try to focus on the good in everything.

From east to west B-road challenge

Matthew Hollis, Area Support Co-ordinator for the MND Association completed an epic 10-day driving challenge using only B-roads and a compass to raise money and awareness of MND.


Cookie, Matthew's beloved Citroen 2CV

Matthew started his challenge at the most eastern point of England, Ness Point in Suffolk. Avoiding all main roads and navigating with just a compass – and the sun when it wasn't hidden by clouds – Matthew drove to the most western spot in Ireland, Dunmore Head in County Kerry in his beloved Citroen 2CV named Cookie.

Matthew said: "It would have been far too simple to have done it in an ordinary car. Cookie was my first car when I was 16. I paid for it with my paper round money. It's probably clocked up around half a million miles since then.

"Thankfully everything went to plan but it wasn't without challenges. Day four was the toughest day. I'd had a few mechanical issues and needed to get the brakes fixed. So I was running behind and desperate to get to Wales to make the ferry crossing. You never really know where a road will end up, and I ended up in an orchard where Cookie got stuck.

"By the time we got Cookie out it was 1am, far too late for a campsite. So, covered in mud I ended up sleeping in a multi-story car park. I lost time the next day as well because I had to fix the drive shaft. That was one of the days where I didn't think I'd make it.


Matthew Hollis ASC for the MND Association

"When I finally got to Dunmore Head on day 10 after a series of wrong turns, I felt euphoric. I'm delighted to have raised over £3,000 for the Association and I'm already thinking about my next driving challenge. I think this one might involve altitude."

Advanced care planning

MND guides can help

Advance care planning involves discussing, documenting and respecting the wishes and preferences of people with MND regarding their future care. It involves making informed decisions about personal, legal and financial issues, as well as future treatments.

Advance care planning helps ensure person-centred care that respects the person's wishes. It also helps family members by providing clarity over actions to take in the future if the person loses the ability to make decisions for themselves.

We have resources to support people with MND and professionals to have these important, but difficult conversations. Our comprehensive and candid guide, *End of life: a guide for people with MND* is aimed at helping people with MND plan ahead and communicate their end of life decisions to family and professionals. We also have guidance on planning for future care and how to create an Advance Decision to Refuse Treatment (ADRT) in *Information sheet 14A – Advanced Decision to Refuse Treatment (ADRT)* and advance care planning.

For health and social care professionals, our *Advance care planning for MND* booklet includes information and practical strategies to help professionals effectively support advance care planning for MND.

CARE INFORMATION UPDATES

MND Checklist

Our new web page is an online version of our printed *MND Checklist* to help you think about your needs following an MND diagnosis. Our print version has also been updated. See the new page at: www.mndassociation.org/mndchecklist

Revisions

The following information sheets have been updated. See Information sheets at: www.mndassociation.org/careinfo

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

Inherited MND and genetic testing

Our new booklet explores genetic counselling and genetic testing for people who have a family history of MND. Visit *Guides and booklets* at www.mndassociation.org/careinfo

We also have an article on inherited MND on page 22 of this magazine.

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:

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

We have also published a new resource, *Advance care planning for MND*

Advance care planning (ACP) involves discussing, documenting and respecting the wishes and preferences of people with MND regarding their future care. ACP involves making informed decisions about personal, legal and financial issues as well as future healthcare. This booklet includes information and practical strategies to help professionals effectively support advance care planning for people with MND.

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

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. If you would like to get involved, you will have opportunities to feed into a range of different content and formats. To find out more contact infofeedback@mndassociation.org

“For me, it’s a page that tells people about Dad”

Jay Lucas’s dad Trevor, died from MND in 2008. His family set up a Tribute Fund in Trevor’s memory and have taken on several fundraising events over the years.

Jay describes his dad as being ‘pretty brilliant’. He said: “Dad loved to play golf. Well, he loved it up to a point. He loved it up to, in his words, ‘the best round of his life’. And then after that, he didn’t like it so much because it got quite hard to keep up with that level.”

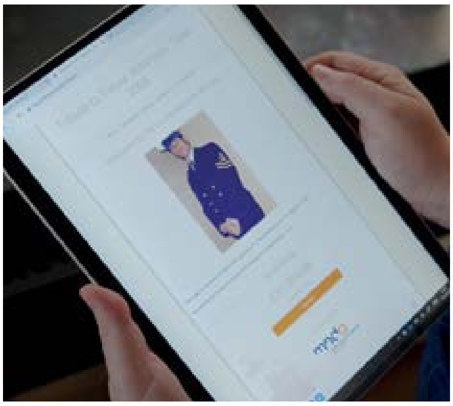
> **“There are lots and lots of people who have helped us to raise this money over the years and I wanted to show them, and everyone else, what their kindness and time and donation had amounted to.**

Jay and Trevor

Jay has taken on several fundraising challenges in his dad’s memory, including a charity golf day, shaving his head, raffles and doing the London Marathon twice. His dad’s Tribute Fund records everything in one place.

Jay said: “There are lots and lots of people who have helped us to raise this money over the years and I wanted to show them, and everyone else, what their kindness and time and donation had amounted to.”

Trevor died in 2008, just a little over a year after his formal diagnosis. Being able to help others facing an MND diagnosis and improve their quality of life is what motivated Jay and the people around him to fundraise. Jay said: “The help that we received from the Association and from these wonderful, wonderful people – other people need that.”



Trevor’s Tribute Fund page on a tablet

A Tribute Fund is a special place online where you, your family, and friends can remember your loved one and raise money to fight MND in their name. Having set up a Tribute Fund in memory of Trevor in 2022, Jay said: “To me, a Tribute Fund is a single place to remember somebody, but it also involves others in the work that you’ve done or the work that others around you have done to support the cause. A Tribute Fund really helps give everyone around you a sense of achievement, and that will boost you as well.”

The Trevor Robinson Tribute Fund has raised £31,394 from Jay and his family’s fundraising over the years. Jay said: “It’s nice to know that all this money is helping people. Not *will*. Is.”

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

NHS Continuing Healthcare
Ongoing care assessment

NHS Continuing Healthcare, known as CHC, is a package of ongoing care arranged and funded by the NHS. CHC can be similar to a support package from adult social care services but covers health needs as well as social care needs.

To qualify for CHC, you must be assessed as having a 'primary health need'. This usually means that you have more complex needs than can be met by adult social care services. You may be able to get CHC if:

- you have complex health issues and a high level of skill is needed to manage your care and treatment
- you need ongoing care
- your condition is changing quickly and this is causing concerns in managing your care.

The assessment for NHS Continuing Healthcare is complex, detailed and can take a while to complete. Understanding how the system works, and what makes someone eligible for CHC can make the process smoother. The MND Association has a range of resources available to help people applying for CHC, including an animation, a peer support group and information sheets. These have all been brought together on our new CHC webpage www.mndassociation.org/CHC

> **The process can be daunting but it can also be very worthwhile for your family's financial affairs. Be prepared for a struggle, but if you are successful the results can be game changing, given the cost of care today.**
>
> Dave Setters, person living with MND

Supporting health professionals
to deliver new psychological therapy

The COMMEND study, funded by the MND Association and National Institute for Health and Care Research (NIHR), has shown a particular type of psychological therapy – Acceptance and Commitment Therapy (ACT) – can improve quality of life for people with MND, when given alongside usual care.

In direct response to this study, conducted by researchers at the University of Sheffield and University College London (UCL), the MND Association is committing to facilitating ACT training for psychologists who work with people with MND.

ACT is a form of psychological therapy that helps people to learn new ways of handling distressing thoughts and feelings. It also helps people to develop ways of taking part in activities that are important and meaningful to them.

Professor Chris McDermott, Professor of Translational Neurology at the University of Sheffield, Honorary Consultant Neurologist and joint lead of the trial, said: "While we work hard for a cure, it is essential we support those living with MND now. The COMMEND study shows that tailored psychological support can have a major impact on the quality of life of those people living with MND."

Professor Rebecca Gould, Chief Investigator of the study and joint lead of the trial, said: "In the absence of a cure for this devastating disease, interventions aimed at helping to improve the psychological wellbeing and quality of life of people living with MND are crucial.

"This study provides strong evidence that Acceptance and Commitment Therapy can be a valuable tool for improving quality of life for the 5,000 people who are currently living with MND in the UK."

“All I wanted to do was comfort her”

Paul’s book honours his wife, Lennie

YOUR STORIES

For retired prison governor Paul Laxton, caring for his wife Lennie was not just a fight against MND, but also a struggle to work around stringent Covid restrictions after she was hospitalised. Lennie was diagnosed with MND on 15 June 2020, while Covid restrictions were in place. These restrictions limited the time Paul could spend with her during her final month.

To pay tribute to his late wife and help manage his grief Paul has written a book, as he explains: “Writing is my one and only talent. My initial reason for writing was to honour Lennie’s memory, but it also became quite therapeutic.

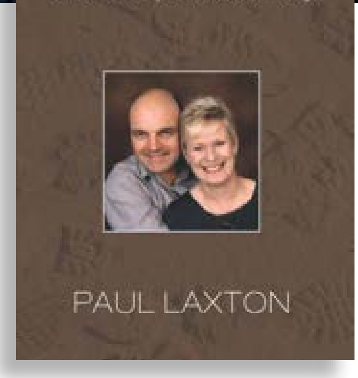
“It gave me a purpose as I faced my first winter without her. I went back through emails, texts and any documentation I had. I hope by sharing our experiences in a book, it will help others.”

Lennie’s progression with MND was rapid and she died on 15 June 2021 exactly one year after receiving her diagnosis. She spent her last month in hospital following a fall. Paul said: “I had to wait 14 days before visiting her. Then I was restricted to weekly visits and had to wear full PPE. Only towards the end did they relent and grant me daily visits.

“I suppose I was lucky I even got to visit. She wasn’t allowed anyone else, including her son, so they were never able to say goodbye. During the visits I looked more like I was going to Porton Down than a hospital ward. I’d have a goldfish bowl on my head and could hardly hear what she was saying. It made meaningful communication almost impossible. It just felt like there were so many barriers when all I wanted to do was comfort her.

“I couldn’t beat the system, so even though it was a time when emotions were running very high I had to be careful. The most important person was Lennie and I couldn’t let anything get in my way of seeing her.”

Paul and his wife Lennie, who died from MND in 2021



MND:

One Couples’ Journey

PAUL LAXTON

Paul’s book, MND: *One Couple’s Journey* is available on Amazon

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Look out for our **BBC Lifeline appeal**

The MND Association has been awarded its first ever *BBC Lifeline Appeal*, which will air on BBC1 and BBC2 in October.

The 10-minute fundraising appeal will feature people affected by MND who have been supported by the Association, and provides a unique opportunity to raise awareness of the disease with viewers who may not be familiar with MND or the Association’s work. We’ll be sharing more information about our *BBC Lifeline Appeal* on our website and through our social media channels over the coming months, so please do keep a look out and support the appeal if you can.

MND world record breakers
in a six-person costume

A 12-legged caterpillar, named the 'Philapillar' in honour of Phil Rossall who died of MND last year, has scored a Guinness World Record for completing the fastest marathon dressed in a six-person costume.

As reported in the last edition of *Thumb Print*, the owners of those six pairs of legs - Rich Bidgood, Hugh Tibbs, Nick Wright, David Mills, James Bewley and Marcus Green – had already broken the world record for a half marathon dressed in a six-person costume.

They set their sights on the full marathon record. And, at the Manchester Marathon in April, they knocked an incredible 87 minutes off the record – and raised £12,000 for the MND Association.

The challenge wasn't without incident, as Phil's wife Brenda explains: "David had been in bed with a virus but was determined to run. Then there were a few little issues on route, like Marcus getting cramp in both legs two miles from the finish line – getting the Philapillar to stop when you're the one at the back is no easy task!

"They beat the previous record finishing in 2 hours 57 mins 30 secs, which as any runner knows, is a good time for a marathon, even without being tied to five others and not being able to see your feet! The support from friends, family and the Manchester and District Branch of the MND Association was fantastic."

The Philapillar dominated much of the coverage of the Manchester Marathon with features on ITV, BBC, radio and local press. Brenda continues: "I'd like to thank everyone involved and, in particular to Marcus, who organised it all. Phil knew how important it is to work towards a cure for this disease and he would be so proud of their achievement and delighted that they, in particular, wanted to break Guinness World Records in his memory."

To make a donation visit www.justgiving.com/marcus-green13 or scan the QR code.

Taking on challenges
with MND

Nicholas Deane was diagnosed with MND back in November 2023. Not allowing the disease to take control, Nick decided to take on some challenges, the first one being the MND Association's challenge to Run25 miles in December. Not only did Nick complete the 25 miles, he ran many more, while raising more than an incredible £11,000.

> **"Time is short, if something tempts you, go ahead and do it, you will gets lots of support from the MND Association too.**

Nick was due to run the London Marathon this year, but instead, a friend suggested taking on the National Three Peaks Challenge. Being Nick, he decided to enrol as many friends and family as possible to take on the challenge with him. Nick recruited over 30 people who came together in May to join him in completing the epic task.

Nick knows first-hand the effects MND has, not only on people living with it, but those affected by it too. He wanted to organise the challenge with like-minded people in order to raise as much awareness, and of course money, as possible, in order to help find a treatment and ultimately a cure.

Nick is very grateful for the support, advice and guidance he received from the MND Association forum, and from his local Regional Fundraiser Amanda Devlin. Nick said: "Time is short, if something tempts you, go ahead and do it, you will gets lots of support from the MND Association too."

See Me/Hear Me
The extraordinary life of Sarah Ezekiel

The story of Sarah Ezekiel's extraordinary life was transferred to a theatre stage in Manchester in a glorious production written and directed by Sarah herself.

Sarah is a familiar face to many in the MND community. Diagnosed with MND over 20 years ago when she was pregnant with her second child, Sarah has gone on to become an established visual artist, who communicates and creates art using eye-movement.

Based on Sarah's memoir, See Me/Hear Me uses drag to explore the life and imaginative inner-world of Sarah's experience with MND. To bring the show to the stage, Sarah worked with anthropologists, Andrew Irving and Cheddar Gorgeous, drag artists Pixie Polite, TeTe Bang and Duane Nasis and composer Alex Herd, who is also living with MND.

> **Melissa helped me to complete my memoir. Once that was written it just took a few months to put the show together.**

The project began when Andrew, an Anthropology Professor at Manchester University asked Sarah to create an eyegaze picture for a book he was writing. When Sarah met Andrew and his partner Melissa, a writer, in September 2019, Sarah mentioned she'd started writing her memoir, but hadn't touched it for years because she couldn't face going back to 'her bad place'.

Encouraged by the pair Sarah returned to her memoir, as she explains: "I started it in 2005 when I got my first Assistive Technology Computer purchased by the MND Association. I was using a chin switch and EZ Keys software. I only started using eyegaze in 2010. Melissa helped me to complete my memoir. Once that was written it just took a few months to put the show together.

"The night of the performance was really magical, especially at the end when everyone got up and danced with us. I also finally met Daniel Brocklebank who I've been in touch with on social media for years. Peter Ash is lovely too and it was nice to get a chance to tell them they're doing a fantastic job of portraying MND on Coronation Street.

"I'm so touched at how everyone came together to make the show a success. Cheddar Gorgeous asked his drag queen friends to join us, and TeTe made my costumes. The music was also a big part of the show. Alex used the script to write the music. He's really talented so I feel lucky we are working together."

Composer Alex was diagnosed with MND in 2021 when he was just 30. Alex said: "My neurologist told me that a documentary maker, Phil Cox from Native Films, was looking for people with MND to get involved in a film he was making. He was also in touch with Sarah and that's how we connected. During one of our conversations I played him my music. He knew Sarah was working on the show and he proposed I make music for it.

"Sarah had written the script and there were certain pieces that needed original music underneath her monologues. This is the first time I've made music for someone else. It was challenging – I had to make a lot of music in a short space of time compared to how long I would normally spend. The time constraints and pressure forced me to not second guess myself and go with my gut.

"Being part of this show has built my confidence and it felt nice to hear the positive feedback. It was surreal to be in the room and watch the audience listen to my music. It helped me to find a little more belief in myself.

The cast with Sarah seated in the middle

"Sarah gave me a lot of freedom in terms of what I could do. Sarah's writing chimed with my own experience of being diagnosed with MND. Sarah is honest about how she feels – she talks about anxiety and depression, and feeling like she is never going to be loved

Alex Herd who composed the original music played throughout the performance

Performers from the drag show. L-R: Duane Nasis, TeTe Bang, Alex Herd, Pixie Polite, Sarah Ezekiel and Cheddar Gorgeous.

> **The night of the performance was really magical, especially at the end when everyone got up and danced with us. I also finally met Daniel Brocklebank who I've been in touch with on social media for years. Peter Ash is lovely too and it was nice to get a chance to tell them they're doing a fantastic job of portraying MND on *Coronation Street*.**
>
> Sarah Ezekiel

again. I relate to a lot of those feelings.

"Like Sarah, I feel like living with MND has encouraged me to create more, and not second guess myself. I'm more willing to put myself out there. I might not have that much time left, so I need to trust in my own abilities. I've gained so much through the show, but most of all I've gained a new friend who has helped me adjust to life with MND."

Alex's husband Craig feels like he has also been personally helped by the show. Craig said: "I was worried about how much of Alex's spark and personality would be hidden by the illness. But meeting Sarah and seeing how despite MND removing her ability to talk, walk or use her hands, you can still see her cheekiness and her love of life. That's made me feel less anxious."

There are now plans to bring the show to London, and Sarah is showing no signs of taking a rest. Sarah said: "I believe MND has been the making of me and I don't think I would have achieved so much as I have now. I never imagined I'd end up as a drag queen called Ms MaNDy!"

Sarah Ezekiel with Coronation Street stars Daniel Brocklebank and Peter Ash

Members of the Manchester Branch pictured with Sarah Ezekiel. Back row L-R: Sylvia Hinde, Nigel Mills, Stephanie Mill, Sue Thompson, Liz Groundland

Alex Herd and his husband Craig

Caring for Mam
Rosie shares her story

At just 23, Rosie Hollins became a full-time carer to her mum Alyson after her MND diagnosis. Rosie shared her experience of caring for her mum as part of Carers Week in June. Here, she tells her story in her own words.

Mam was a very independent, hard-working woman. She was always multi-tasking and calm under pressure, always smiling and positive, and there for anybody who needed her. Mam loved trance music and dancing. She got me into it and taught me how to dance when I had no confidence.

Mam loved camping and being outdoors and we used to go running in the mornings together. She adored her family and she spent most of her adult life raising me and my brother Ryan.

Whilst looking after Mam, lots of people said to me; 'I don't know how you did it for nine years'. But for me, it wasn't a big deal. I was with my best friend, and I was in the comfort of my own home, and I wouldn't have wanted it any other way. I didn't see it as a sacrifice, it was a blessing to be able to spend that time with her.

Mam's hands were affected first. Then she started to find it more difficult to use her legs. Mam started having tests done and I realised things were serious when she was offered MRI scans and a lumbar puncture.

We watched the *Coronation Street* storyline together and I thought it was really good what they did with Paul when they said he was drunk, because it's so true. People make judgemental assumptions and it's literally what happened to my mam. That was hard to watch.

Allyson, Rosie's mum who died from MND

There's lots of little things we take for granted that don't really get mentioned. It's simple things we encounter every day that are a massive deal to someone who has MND. For example, having an eyelash in your eye, you're stuck like that until somebody can get it out. Having a cramp or an itch you can't get to. Your glasses falling down your nose, you can't do anything about it. Even when these things happen, imagine the difficulty of spelling out the alphabet trying to tell someone the issue.

Rosie Hollins, who cared for her mum Allyson

I think that one thing people forget is having a terminal illness does not shield you from day-to-day life. You still get hurt by people, have to watch loved ones get ill and have financial worries etc. The only difference is you don't have a voice and can't take direct action yourself. We cried a lot. It's so difficult when you care 24/7 for nine years. As things deteriorate, you feel completely on your own.

I'd recommend face-to-face or online support groups. After I lost Mam, I participated in an organised fundraiser and engaged with many amazing people. The support I received was outstanding and it really helped me through some of my darkest days. The Facebook page was the first time I felt like I was surrounded by like-minded people who understood me and were experiencing the same emotions. I gained a lot of strength and reassurance from it and wished I had engaged in something similar sooner. I would definitely recommend people utilise any social support platforms accessible to them.

Geoff's 'Wakey Wakey'

A party to celebrate life

Almost 100 mourners gathered together to raise a glass to their dear friend, relative, colleague and acquaintance Geoff Young. Geoff always loved a party and his brilliant sense of humour would typically place him right in the middle of the action.

Saddened by the thought of missing his own funeral, he decided to host what he called 'Geoff's Wakey Wakey'. On 18 May Geoff, dressed in sparkly jacket, warmly greeted his mourners. For Geoff's friends and family it was a moment they'll treasure forever, and for his mourners, it was a funeral they'll never forget, as his wife Helen explains.

Caption

> **It was incredible to see so many people from all walks of Geoff's life under one roof, including our lovely MND Association volunteer Sue Plummer.**

"A diagnosis of prostate cancer, followed by a diagnosis of lymphoma of the brain, followed by a diagnosis of MND in 2020 when Geoff was 66, has made the last few years tough for both of us. But, throughout it all Geoff has maintained his positivity and humour.

"As Geoff's symptoms have progressed, we've adapted and worked our way through it together. Geoff's speech is quite poor. His breathing and swallowing are also badly affected and he now uses a PEG for feeding. I see his frustration at not being able to do what he used to. But whatever happens we generally find something to laugh about.

"We don't talk about death very much. Of course we know it will happen, but it's not something Geoff is comfortable to discuss. That's why it was such a surprise when Geoff first said he was sorry to miss his own funeral. When he brought it up again later in conversation I knew he was serious, so I suggested we organise a funeral he could attend. Immediately he said: 'let's call it my Wakey Wakey'.

"My daughter Amanda and daughter-in-law Hannah are very good at planning and sent invites out to everyone, including people Geoff worked with years ago. Planning Geoff's wake has actually given us all something to look forward to. We also wanted it to be a fundraising event for the MND Association. Amanda and her husband Anthony organised a raffle that raised £555 and a further £270 was put in the collection bucket on the bar. It was an evening of music, laughter and entertainment. They also organised a roulette table and Geoff's son Matt and his wife Hannah organised a photo booth and magician.

> **There were people that Geoff hadn't seen in 20 years. It was such a special moment. There were a few tears, but they were happy tears. It was an evening we will never forget.**

"It was incredible to see so many people from all walks of Geoff's life under one roof, including our lovely MND Association volunteer Sue Plummer. There were people that Geoff hadn't seen in 20 years. It was such a special moment. There were a few tears, but they were happy tears. It was an evening we will never forget."

Getting support quickly to those who need it

The events, fundraising challenges and one-off donations raised by the Manchester and District Branch of the MND Association funds its provision of local support.

Last year the branch contributed £61,000 towards grants for people affected by MND. Committee members Stephen Mears, Sue McCormick and Sylvia Hinde, fondly known as the Three Musketeers, review all grant applications and respond within 24 hours. Sylvia, also an Association visitor (Av), shares how the branch provides support.

Pictured left to right: Sylvia Hinde, Andrea McEntee, Area Support Co-ordinator and Branch Treasurer, Stephen Mears present staff with a donation to Bolton Hospice

We know only too well how fast- moving MND can be. That's why we aim to be swift in getting grants into the hands of those who need them. Recently we replaced a broken tablet which a man living with MND relied on to communicate. Time was of the essence so we made sure to approve the request just hours after we received it.

In the nine years I've been a volunteer, we've funded a huge range of items. It's very personalised support where we can fund something that will really make a difference to the person with MND, their carer or family.

I first got involved with the Association after caring for a dear friend who had MND. At the time, the Association was piloting a benefits scheme in Manchester so our treasurer Stephen and I did the training and we rolled it out across the district.

In Manchester, we are still very proactive in ensuring people are claiming the benefits they are entitled to. Stephen and I aim to train all AVs to complete *Personal Independence Payment and Impact Assessment* forms on behalf of people.

At the moment I'm supporting 19 people with MND on a one-to-one basis. I'm one of three volunteers who each take turns to attend the weekly MND Care Centre Clinic. It's great we can be part of the clinic. The MND nurses encourage people who are newly diagnosed to speak to us.

Many people are surprised at the range of support we can offer from financial to emotional help. I tell them about the support meetings, the grants we fund and explain the Av role. We also invite them to become members of the Association. I tell them there is strength in numbers and if we can have a strong membership it will give us a greater voice to influence government.

Since the cost of living crisis, we've seen the type of grant applications change. It's a sign of the financial stress people are under. A few years ago we'd get a lot of applications to enable families to have a special moment, possibly a holiday or weekend away. Sadly, now it's more about day-to-day living, either pieces of equipment or support with paying the bills.

Recently we provided a grant towards a lady's energy bills. She'd been caring for her husband for the last three years. Her husband was always cold but she was fearful of putting on the heating. Being able to help her so directly was humbling for all of us. Reading the thank you emails and texts from people we've supported always brightens my day.

We're here for everyone affected by MND. And while much of our support is concentrated in Manchester and the surrounding areas, through providing funding to research projects and to the CEO's appeal, we are also proud to support the wider MND community.

Stephanie Mills, Nigel Mills and Sylvia Hinde collecting a cheque from staff at the Mason Arms, Duckingfield

My life-changing technology

Headset drives Eoin's wheelchair

A grant from the MND Association has enabled Eoin Egan to drive his wheelchair using a headset, providing independence despite his limited physical ability. Here, Eoin shares the difference this technology has made.

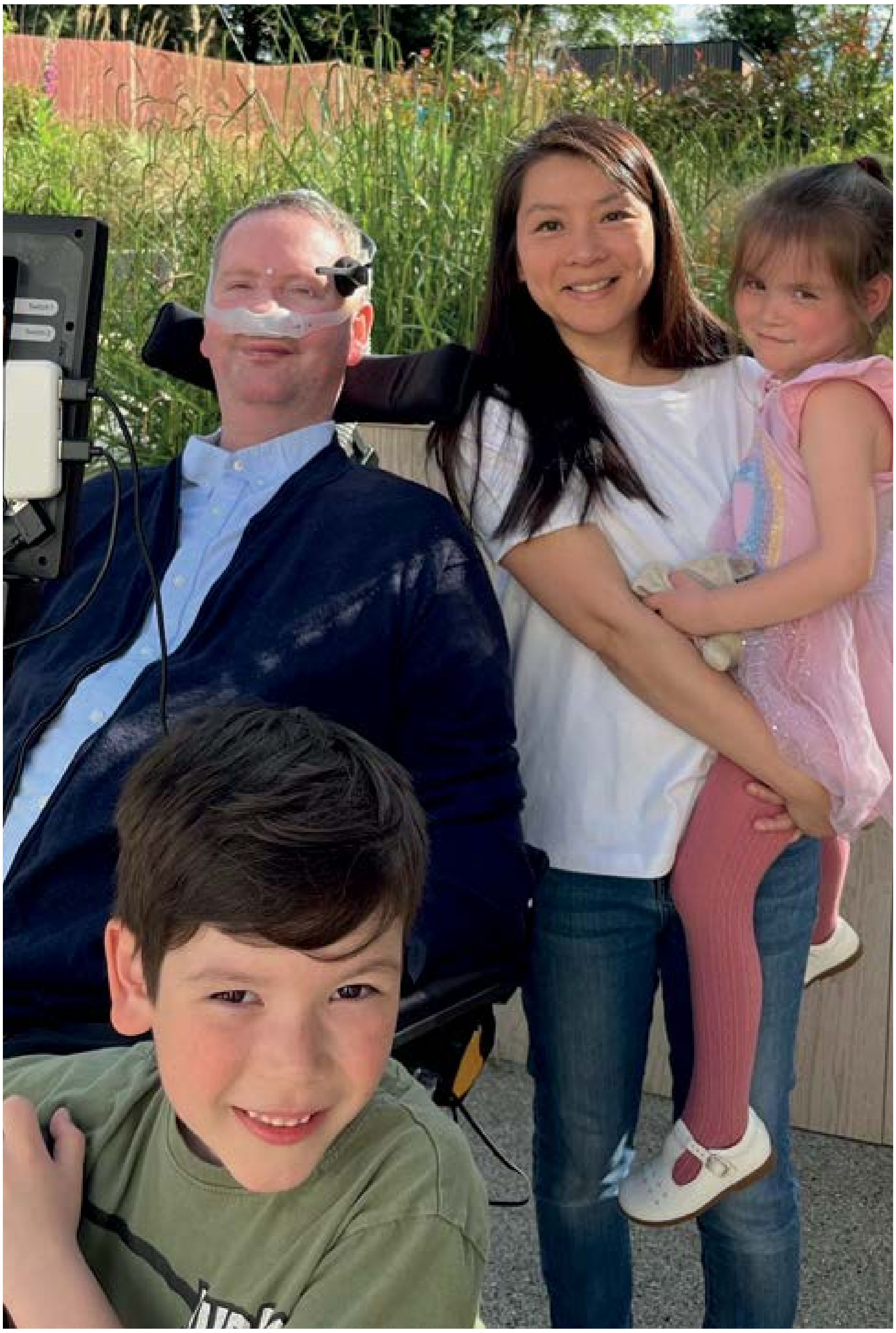
I've benefitted enormously from integrating two technologies to enable me to use a head-joystick to drive my wheelchair. My physical abilities are limited, so I was introduced to the Vigo Head Drive by the MND Association. It comes with a headband that acts as a head joystick and a black cube with a small display wired to the wheelchair controls.

Once it is set up you can travel on flat ground with good manoeuvrability. However, if the ground is sloping the headset can't distinguish between that and intentional head tilting. I don't have the head or neck strength to counter the leaning. I'm able to go straight up and down short ramps relatively easily, but I suspect patients with strong head/neck control will be better on sloping ground.

To use the headset I combine it with switches I can operate. Smartbox has a range with a 'try before you buy' service. They couriered a selection to my home including the Cenomy switch. With no movement of my limbs and weak finger movements, I need switches which don't become out of reach when I hit a bump, recline, or if somebody brushes against my arm.

> **I've benefitted enormously from integrating two technologies to enable me to use a head-joystick to drive my wheelchair.**

The Cenomy switch can be strapped to your body and senses electromagnetic pulses from voluntary muscle twitches which send a signal to the wheelchair.



Eoin pictured with his family

The control box has a dial to increase or decrease sensitivity, an on-off switch with or without a beep, and an option to delay the signal.

When a signal is successfully received from the muscle twitch and sent to the wheelchair, the control box flashes a green light and beeps. The device is wonderfully uncomplicated and has a 1980s retro look and feel. The complicated part is hooking it up to awkward, challenging patients like me! Once the right technique to fix the sensor to the patient is found and appropriate training given, it can become familiar for carers to fit, but I won't downplay how difficult that process might be for some. Indeed, I've been told this is why it's not widely used or known. However, with the assistance of my wheelchair technician, wife and carers it works for me and is, frankly, life-changing.

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.

£1,500

Virtual success: In January, Liam Foster took on a virtual cycle challenge from Hull to Wembley Stadium, inspired by Rob Burrow CBE and his friend Craig, recently diagnosed with MND. Using a static bike at his local gym, Liam pedalled 600km during the month with Craig joining him on the penultimate day. Afterwards, Liam said: "I loved the challenge; it was a truly special month. Throughout, I was inspired and driven by messages received from people living with MND." Liam raised £1,500 and is already planning his next challenge.

£1,900

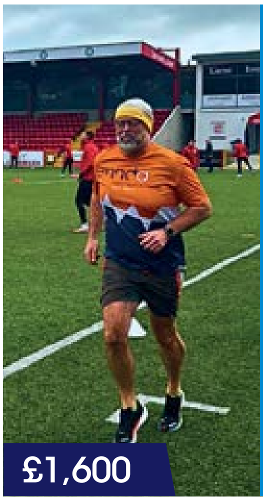
Skydive adventure
Leah Kennealey braved a skydive to raise over £1,900 for the Lincolnshire Branch in honour of her grandad who is living with MND. She said: "I think my grandad was very proud of me for choosing to skydive and very pleased with the amount of money and awareness I managed to raise. It meant the world to me that he could be there on the day to watch."

£780

Raising a cuppa: In April, Kimberley Murray organised a successful coffee, cake and raffle fundraiser at Greasby Community Centre in memory of her mum, Irene. Kimberley, her family and friends raised an amazing £780 for the Merseyside Branch and for MND research.

£5,000

Island trek: Last year, Sophie Acreman from Cumbria was planning to complete the Lake District Ultra Challenge in honour of her mum, who had MND. Unfortunately, just before the event Sophie had to withdraw as her mum's condition deteriorated. Determined to honour her promise, in May, Sophie took part in the Isle of Wight Ultra Challenge, trekking 100km around the island in just two days, in memory of her mum and raising over £5,000.



£1,600

Lent run: Glenn Mann ran 5k per day during Lent to raise over £1,600 for the Northern Ireland Branch in honour of his friend Raymond who is living with MND. He said: "Raymond has been diagnosed for some time now and I see how brave he and his whole family are and how they conduct themselves. It inspired me to help them and others like them living in Northern Ireland."

£2,189

We will rock you!: In April, the Wirral Group, NE Wales and Merseyside branches held a Rock Choir Concert at South Wirral High School compered by branch member Ian Gibbons who made sure the evening went with a swing. There was a raffle with prizes generously donated by Everton FC, Tesco, Venue Cymru, Theatr Clwyd. In total, the evening raised £2,189.

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**

£1,845

Half century challenge: Ed Hargreaves completed an incredible 52 events in 50 weeks to mark his 50th birthday. Challenges included running, rowing, cycling, stepping, swimming and climbing. Afterwards Ed said: "It's been the toughest year of my life. Long days, with no rest or recovery, and the relentless nature of the challenges. I've been hot, cold, wet and tired most of the time and on one occasion more than a little scared. Any regrets? No. Would I do it again? Absolutely not!

£1,600

In memory of Mum: Seema Sharma ran the Cambridge Half Marathon to raise over £1,600 for the Association. She took on the challenge in memory of her mum, Raksha Devi Sharma, who died in 2012. She said: "The Cambridge Half Marathon is a beautiful route and a strong lasting memory with Mum is by the River Cam on Jesus Green, together with Dad. I hope, as a former neuroscientist, I can help fund a research breakthrough to identify disease tipping points, develop treatments and prevent MND."

£3,000

Plymouth pals: Nick Phillips, who is living with MND, got together with 20 of his friends in April for Run Plymouth. Most of the group were novice runners, many completing personal challenges on the day. Nick himself completed the 5k course. As well as raising over £3,000, Nick said: "I realised that I am cared about and supported by my pals, that's been emotional for me."

£6,000

Race night: David Wilson and his family raised over £6,000 with a race night in honour of his mum who is living with MND. He said: "My mum has always been one for doing things for other people. When she was initially diagnosed she said she would like to raise some funds for the MND Association to help people and that message stuck with me. My mum really enjoyed it and we were amazed by the goodwill and generosity of all our family and friends."

£27,000

Lighting the way: Ben Lighting, who is living with MND, and his wife, Lucinda, organised a team of around 50 friends and family members to take part in the Guildford 10k Run last October raising over £26,500. The family have since held a golf day in Woking raising a further £27,000. All funds raised are to be shared with My Name'5 Doddie Foundation.

£9,000

Right on track: At Roedean School Brighton, Year 8 embarked on an ambitious challenge to cover 777km round the track within 24 hours, with a fundraising target of £7,777. The whole school rallied behind the team, who camped out in the sports hall and ran all through the night. They smashed both targets – covering a massive 3,079km and raising £9,000!

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.

A right Royal occasion

You may recognise Mike Sumner and his wife Zoe from our current awareness campaign. The couple were special guests at a Buckingham Palace Garden Party in May, in recognition of their commitment to raising awareness of MND. Mike said: "It was a really nice day and still quite surreal to think we were there. And that we met the King and Queen!"

It's never too soon to start planning for Christmas

We hope you and your friends enjoy looking through our new Christmas catalogue packed with a delightful range of festive cards and wrap, inserted in this issue.

New for 2024, there's a super cute puffin soft toy to purchase. Wearing an MND Association branded scarf, this adorably, soft plush Puffin would make an ideal Christmas gift!

Whatever products you choose, you can be safe in the knowledge that every penny of profit, together with any donation you send, goes directly towards improving the lives of all people affected by MND.

Online orders open 1 August at https://shop.mndassociation.org

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

For my amazing brother Del

You are amazing
I have to say
Your positive thinking
Gets you through each day
You could give up
But you never do
And your sense of humour
Still shines through
MND is a challenge
You cannot mend
But your inner strength
Will get you to the end
Most of us would just give in
Knowing MND will eventually win
But you appreciate precious moments
Every single day
Even MND can't take them away
You have gone through the stress and strife
And I'm glad that you are in my life
You're a great person
Like no other
And I'm so very proud
That you're my big brother

My love always, x sis x
Written by Melanie Hunt for her brother Del, who is living with MND

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 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.

Episode 31: Tanya Curry, one year on
A special anniversary episode in which our Chief Executive Tanya Curry speaks with Tanya Arnold, sports journalist and patron of our West Yorkshire Branch. Tanya discusses her tenure so far, her passion for supporting people affected by MND, and her ambitions for the Association in 2024 and beyond.

Episode 30: *The Love Inside*
In this episode, host Helen chats to the MND Association's Director of External Affairs Chris James to find out more about our latest awareness campaign, the reasons behind exploring TV advertising for the first time in years and what the Association hopes to achieve from The Love Inside.

About us

The Motor Neurone Disease (MND) Association

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

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

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

Social media

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

mndassociation
mndassoc
mndassoc

MND Connect

Our 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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RUN
60 MILES IN AUGUST

Join our challenge

to run 60 miles this August and support families affected by motor neurone disease

Sign up now and you'll receive:

- **A fundraising pack including FREE technical tshirt**
- **Support from a community of participants in our Run 60 Facebook Group**
- **Access to an exclusive online activity logger to track your miles**
- **Regular updates including virtual rewards**

Participants are welcome to run, walk or wheel their miles. The challenge is completely flexible and can be adapted to suit all abilities.

Raise over £150 and claim an exclusive challenge medal

> **"I loved taking part in the challenge. It kept me moving throughout the summer!"**
>
> 2023 Run 60 MIles in August participant

Visit www.mndassociation.org/run60