THUMBPRINT

NEWS FROM THE MND ASSOCIATION COMMUNITY

SUMMER 2023

Patron Eddie Redmayne says 'thanks for everything you do'

Lesley marks 20 years of volunteering with the Association

Let's talk?
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IN THIS ISSUE:

On the cover: Our patron, Eddie Redmayne OBE chats online with long-service volunteer Lesley Connor, thanking her for 20 years of service while acknowledging all who volunteer their time to support people living with MND.

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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

It's already six months since I joined the team at the MND Association and I'm delighted to have met so many of you, our members, already. Thank you to everyone who has given me such a warm welcome, and for your honesty and openness in sharing your personal experiences, your feedback and your ideas.

While I'm still in the early days of my journey with the Association, in this issue of *Thumb Print* we share the stories of some of our longest-standing volunteers, including Lesley Connor whose 20 years of service was marked by a video chat with our Hollywood patron Eddie Redmayne! Read the story on page 6, and you can watch the heart-warming video of their conversation on our website www.mndassociation.org/awarenessday.

And talking of heart-warming – I was privileged to be at Headingley Stadium, back in May, when when Rob Burrow MBE, carried by Kevin Sinfield OBE, crossed the finish line of the inaugural Rob Burrow Leeds Marathon. What an incredible moment, in a whole day of incredible moments! Seeing the sea of blue and orange on the streets of Leeds, witnessing the kindness of friends and strangers, and talking to some of the 2,300 runners supporting the MND Association showed me the power of our MND community.

That power is something we are harnessing through the creation of our MND Taskforce, in line with our Promise that we will not rest until MND is treatable and ultimately curable. We have convened a team of experts from across our community and beyond, to drive access for patients to emerging treatments. We've been talking about the great strides taken in MND research over recent years. This is the next, and vital, step. You can read more on page 9 and on our dedicated web hub www.mndassociation.org/taskforce.

The Taskforce, our Next Generation Think Tank and our EnCouRage event for early career researchers, taking place this month, are perfect examples of the innovative and collaborative approach which, I believe, are key to providing the answers people affected by MND desperately need.

My team and I are now building on this amazing work, and more already underway, as we shape plans for the Association's future. I look forward to sharing them with you – and delivering on the Promises we have made to the MND community.

Tanya Curry
Chief Executive

Care Showcase at Boughton

Over 60 guests attended the Association Care Showcase held at Boughton House

Our Royal Patron HRH The Princess Royal attended the very first MND Association Care Showcase on 6 June, kindly hosted by His Grace the Duke of Buccleuch at Boughton House near Kettering.

At the event, guests were given an insight into the work of our National Care team and and the support offered to those affected by MND, with a particular focus on our financial support grants. Guests were invited on a tour of Boughton House and were able to view an exhibition showcasing some of the MND Association's support services. People living with and affected by MND shared their experiences of using our services through speeches, panel discussions and posters.

Over lunch, attendees heard from Jennie Starkey, who is living with MND. She shared how, thanks to a Quality of Life grant she has been able to continue wild swimming, something that's helped with her mental health, but had become too costly because of increased fuel costs and the cost of living crisis. She also shared how the Association's Children and Young People's grants have helped two of her children pass their driving tests and complete a Duke of Edinburgh Award.

Richard Long, a former lecturer from Hertfordshire, addressed the guests including The Princess Royal. He shared his story, including the many ways that MND makes life more expensive and his increasing reliance on various equipment. He said: "I was really hoping that I could help the MND Association by sharing how expensive having MND is. People living with MND

The Princess Royal enjoys a joke with guests

Richard Long, who is living with MND

Tanya Curry, Chief Executive addresses guests

House

PROMISE 3
WE WON'T REST UNTIL
EVERY DAY COUNTS

> **We hope we have inspired our fantastic fundraisers to continue to support the Association now and well into the future.**
>
> Nick Goldup, Director of Care Improvement at the MND Association

get wonderful support from the Association. I hope that the organisations who were in attendance are inspired to continue to support the MND Association financially after hearing my story."

Jill Douglas, Chief Executive Officer of the My Name'5 Doddie Foundation, attended the event on behalf of the Foundation, which helps to fund our support grants service. She said: "Our big focus is research, but it's so important that we complement that with helping people who are living with the disease right now.

"By partnering with the MND Association, we're making sure our money's going directly to those who need it most. The MND Association has the expertise, due diligence and contact with families to do that. This was hugely important to Doddie, who always said, 'What about the woman in the tenement who hasn't got the support and network around her that I have?' He wanted to give people the best opportunity to live as good a life as they can with this terrible disease."

Nick Goldup, Director of Care Improvement at the MND Association said: "We were delighted to welcome generous fundraisers, charitable trusts and partners to the inaugural MND Association Care Showcase to thank them for their tireless work to make life easier for people living with MND. It was incredible to hear powerful stories directly from people living with the disease about how our support grants programme makes a difference, and we hope that we have inspired our fantastic fundraisers to continue to support the Association now and well into the future."

The Princess Royal chats to guests

Jennie Starkey, who is living with MND shares her story with guests

HRH The Princess Royal cuts a cake celebrating the Association's £14 million research grant commitment

“Thank you Lesley”

Eddie calls long-standing volunteer

> **Eddie was so effervescent. He was very knowledgeable about MND – it was clear he’d done a lot of research for his role in *The Theory of Everything*.**
>
> Lesley Connor, volunteer

> **It was such a treat to meet Lesley and thank her for everything she has done to support the MND community.**
>
> Eddie Redmayne, patron

Ahead of Global MND Awareness Day, MND Association patron and Hollywood actor Eddie Redmayne took time out of his busy schedule to call long-standing volunteer Lesley Connor and thank her for her years of service.

During the conversation, Eddie, who won an Oscar for his portrayal of our late patron Professor Stephen Hawking in *The Theory of Everything*, chatted with Lesley about her background as an occupational therapist, her volunteering roles and the advancements in awareness, research and technology she has seen over the past two decades.

Eddie thanked Lesley for her 20 years of service to people living with and affected by MND locally, as an Association visitor, and nationally, through her evening volunteering role with our MND Connect helpline.

Eddie said: “It was such a treat to meet Lesley and thank her for everything she has done to support the MND community. As a patron of the Association, and to mark Global MND Awareness Day, it was a real pleasure to acknowledge the tireless work of all who volunteer their time to support people living with MND and those around them.”

While Lesley was nervous at first, she soon relaxed and enjoyed the conversation with the Hollywood star.

Lesley said: “Eddie was so effervescent. He was very knowledgeable about MND – it was clear he’d done a lot of research for his role in *The Theory of Everything*. He spent 20 minutes thanking me for what I do, and I thanked him for his work as an MND Association patron, too. I was very nervous to begin with, but it was a lovely experience.”

The conversation was recorded and the resulting film was shared on Global MND Awareness Day on 21 June to raise awareness of MND and the work of the Association.

You can watch the film at www.mndassociation.org/awarenessday

Global MND Awareness Day

Three events over three days

PROMISE 4
WE WON'T REST UNTIL
YOU ARE HEARD

Global MND Awareness Day is marked on 21 June each year, and is an opportunity to shine a light on MND, and influence the decision makers who are best placed to make a real difference to people affected by the condition.

Over three consecutive days, our Policy, Campaigns and Public Affairs team held events in parliament buildings in England, Wales and Northern Ireland. Through the three events, we wanted parliamentarians and other decision makers to learn more about MND, and, importantly, understand how they can make a difference.

Millie Jenkins, the Association's Senior Policy and Public Affairs Adviser, Wales (right) with Llyr Gruffydd MS who sponsored the event at the Senedd

Day one: Senedd, Wales

On Tuesday 20 June, Llyr Gruffyd MS, who's been personally affected by MND, sponsored our drop-in event at the Senedd. 24 Members of the Senedd (MSs) from across the political spectrum were able to drop-in and discuss issues facing people affected by MND.

These conversations enabled us to share the successful campaigning and research activity happening in Wales. We were delighted to be joined by our campaign volunteers and branch members who were on hand to talk about their work in local communities and the successes they've achieved.

Day two: Westminster, England

On Wednesday 21 June, 65 Members of Parliament (MP) and Peers attended our drop-in event at Westminster, including the Minister for Health and Social Care, Helen Whately MP, and Shadow Minister for Health and Social Care MP, Andrew Gwynne MP. They heard from campaign volunteers about a range of issues that matter to people affected by MND.

MPs and Peers were able to visit five stations, each representing an MND Association campaign. This included our work on cost of living, our calls for better support for MND carers, improved access to benefits for people living with MND, and the importance of timely home adaptations through our *Act to Adapt* campaign. Alongside this, we also shared our work on research funding and access to new medicines.

People living with MND, volunteers and staff at the Parliamentary event in London

Five volunteers, some of whom are living with MND, attended the drop-in to speak with MPs and Peers about these issues, why they are important to them, and what actions they need parliamentarians to take to bring about change for people affected by MND.

External Affairs Director, Chris James (left) with Andrew Lewer MBE MP (Chair of the all-party parliamentary group on MND)

Day three: Millennium Forum, Northern Ireland

With Stormont still suspended over post Brexit agreements, on Thursday 22 June, we held an event in the Millennium Forum in Derry/Londonderry. Colum Eastwood MP opened the event, and speakers presented on issues including research, clinical trials and general awareness raising. The event was attended by MLAs, MPs, Councillors, MND Association representatives, Branch members, and people affected by MND.

Get involved

If you would like to be part of our work to create positive change for people living with MND and their carers, get in touch by emailing campaigns@mndassociation.org

Share and dare #MNDOverMatter

Alongside a host of events and activities staged on Global MND Awareness Day, we asked people to share and dare to show they believe in MND over matter.

And they did – using the hashtag #MNDOverMatter.

We invited people affected by MND to highlight the inspiring way they push boundaries every single day. People shared their stories of triumph, from opening up about their diagnosis with work colleagues to attending a family wedding.

And we asked others to dare themselves to push their personal boundaries in support of people with MND, perhaps by learning more about the disease or signing up to a fundraising challenge in support of the MND Association.

It's not too late to get involved. Share your story of #MNDOverMatter on social media. Or dare yourself – or someone else – to face a challenge!

353 likes
mndassoc It's Global MND Awareness Day and we're putting MND Over Matter... more
View all 26 comments

Kate Hall
@kategiffard

My wonderful dad was so positive following his diagnosis and for the 11 months he lived with MND. 💙All power to the MND community and families - I see you - it's the club no one wants to belong to. Research is key to find a cure 🙏, thank you @mndassoc 💙🧡 #GlobalMNDAwarenessDay

eyegazeartist
@sarahezekiel

Just been swimming at @AspireCharity with my son. We went when he was a baby after I was diagnosed with #MND. I've kept exercising for 23 years and encourage others to do the same. It was poignant going back with him. #MNDOverMatter

3:04 pm · 21 Jun 2023 · 1,231 Views

TV dramas highlight MND

Actor Peter Ash's character Paul Foreman, has been diagnosed with MND in Coronation Street

Gethin, played by Bob Pugh, in Casualty is living with MND

The MND Association is working with two popular television programmes featuring prominent storylines about characters living with MND.

Viewers of ITV1's *Coronation Street* watched character Paul Foreman diagnosed with MND in April after experiencing weakness in his hand. The storyline will see Paul, played by actor Peter Ash, struggle to come to terms with his diagnosis and it will follow his disease progression, and the impact it has on him and his loved ones.

Meanwhile on BBC1, *Casualty* has introduced a new character who is living with MND. Gethin, played by actor Bob Pugh, has joined the programme as the ex-husband of popular character paramedic Jan, played by Di Botcher..

The Association is continuing to support the *Coronation Street* and *Casualty* teams, providing information to researchers, scriptwriters and the actors involved to ensure their portrayals are as accurate as possible, within the boundaries of a television drama.

For questions or to share your feedback about the storylines, email communications@mndassociation.org

MBE honour for Dr Brian Dickie

Our Director of Research Development Dr Brian Dickie, who was named a Member of the Order of the British Empire (MBE) in the King's New Year's Honours List, has been presented with his medal by HRH The Prince of Wales. The recognition came for 'services to motor neurone disease', after more than 25 years of working at the Association.

During that time, Brian has worked tirelessly to significantly increased both the quality and quantity of collaborative research into MND in the UK and beyond. In 1996, the Association was invested £150,000 in three research projects. Fast forward to 2023 and we now have a total commitment of £20.8 million consisting of 113 grants.

He has transformed our International Symposium on ALS/ MND from a relatively small Symposium and is now the premier event in the MND research calendar for discussion on the latest advances in science and clinical management.

Brian said: "I'm very honoured to have been recognised, but this award really reflects the progress made by the MND research community, which over the past two decades has seen an exponential rise in scientific knowledge about the disease.

"The MND Association has played a pivotal role in this process, not only through supporting vital research, but also in facilitating exchange of information and fostering international collaboration through events such as the International Symposium.

"MND has progressed from being a 'scientific backwater' to take its place at the forefront of neurodegenerative disease research - with increasing confidence among the scientific community that it will also lead the field in the development of effective treatments."

Taskforce launched with focus on emerging treatments

Research technician Vedanth Kumar, SITraN

> **People with MND desperately need some hope. Right now, researchers are talking about being on the cusp of really meaningful breakthroughs and we need to be ready to act as those happen.**
>
> Tanya Curry, Chief Executive

To ensure new and effective treatments are available as soon as possible, we have set up a taskforce of experts, focused on identifying routes for patients to access emerging medicines.

The first drug to come under the Taskforce's remit is low-dose interleukin-2 (IL-2), a repurposed cancer drug which is showing some encouraging results in early clinical studies.

The MND Access to Treatments Taskforce founded by the MND Association, had its first meeting in April. The group comprises people living with MND, representatives from the MND Association, MND Scotland and My Name'5 Doddie Foundation, as well as neuroscientists and specialists with detailed knowledge of drug regulation.

It can take many years for new medicines to go through the research and licensing process, and involve multiple groups, from researchers to pharmaceutical companies, regulators and pharmacists. Even after getting a licence, drugs have to be approved for use by other bodies such as the National Institute for Health and Care Excellence (NICE) in England and the Scottish Medicines Consortium (SMC) in Scotland. Only then can doctors prescribe them on the NHS.

It is the Taskforce's role to investigate and identify the most effective routes through these processes.

Louise Heywood PhD student, SITraN

This project is funded by the Garfield Weston Foundation, the J P Moulton Charitable Foundation, the Batchworth Trust and the John Young Charitable Settlement.

The Association's Chief Executive, Tanya Curry said: "People with MND desperately need some hope. Right now, researchers are talking about being on the cusp of really meaningful breakthroughs and we need to be ready to act as those happen. The creation of the Taskforce is enabling us to pool knowledge, expertise and resources to do everything possible to accelerate access to effective treatments as and when they become available."

MIROCALS: next steps

Currently, only patients from one research site which took part in the Modifying Immune Response and Outcomes in ALS (MIROCALS) trial in the UK, are being offered access to IL-2 via a compassionate use programme.

ILTOO, the French pharmaceutical company which bought the commercial rights to the MIROCALS data, hasn't yet announced whether it plans to provide an early access programme. If it does, this could mean people who were not on the trial may be able to access the drug. The Taskforce is in discussions with ILTOO about this. We will be sharing the progress of the Taskforce on our website www.mndassociation.org/taskforce

Tofersen approved in the United States

In April, Tofersen was approved for the treatment of SOD1 MND in the United States, under the name Qalsody. Tofersen has been specifically developed for MND caused by mistakes in the SOD1 gene, which accounts for around 2% of MND cases.

The approval of Tofersen is a welcome step forward in the fight against MND and provides hope for the pathway to approval for other genetic treatments under investigation in clinical trials.

Tofersen is not currently approved in the UK. The European Medicines Agency (EMA), which approves drugs for use in the EU, including Northern Ireland, is reviewing the data. Since Brexit, the UK regulator can rely on regulatory decisions taken by the EMA. It is expected that any decision about the approval of Tofersen by the EMA will be reflected in Great Britain.

Regulatory approval is only the first hurdle to overcome for a new treatment to be prescribed on the NHS. New treatments must also be assessed by the National Institute for Health and Care Excellence to determine if the treatment is cost effective. Tofersen is currently in the early stages of this process.

Dr Andrew Tossolini, Researcher at University College London

None of this progress would be possible without the continued support of the MND community, the dedication of researchers and generosity of people living with MND, their families and carers. Find out more about Tofersen on our blog: www.mndassoc.org/tofersenapproval

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Care information update

Social care resources

Having your needs assessed through adult social care services can help you access services, information and more.

Our revised animation *What is social care?* can be found along with other introductory animations at www.mndassociation.org/animations

Our revised information sheet *10B – What is social care?* can be found in our list of information sheets at www.mndassociation.org/careinfo

6A – Physiotherapy and exercise with MND

This sheet has been updated. Exercise cannot reverse the impact of MND, but it can help with flexibility and to strengthen muscles not yet affected. Find this sheet, and more about movement and mobility at www.mndassociation.org/mobility

MND Buddies

Our activity hub for young children can help them learn about MND, through gentle stories, games and things to do. This hub has been checked and updated. We love receiving artwork, poems and short stories from children aged from four to 10 to display in the hub galleries. Go to the *See it* pages to find out more, at: www.mndbuddies.org

Safety at home web page

See our new page about keeping safe at home with MND or Kennedy's disease at www.mndassociation.org/safety

You can read more about this in our article on page 32.

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:

- *Supporting children and young people*
- *P3 – Saliva control*
- *P5 – Providing medical evidence*
- *P9 – Oral suction*

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

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 ongoing in 2023. If you would like to get involved we would love to hear from you.

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

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

Focus on MND research in Wales

> **What we have learnt tonight is that there is hope, there is a future and there is some light on the horizon.**
>
> Eluned Morgan, MS for Health and Social Services

Our Campaigns team outside the Welsh Parliament

In May, a member of the Welsh Parliament, Russell George, hosted our event at the Senedd, to share the recent developments in MND research in Wales.

With eight MND studies taking place in Wales, Caroline Bidder, Lead Care Co-ordinator of the South Wales MND Care and Research Network, talked about the increased amount of clinical MND research happening in the country.

Laboratory research was also covered at the event by speaker Dr Owen Peters, Lecturer in Dementia and MND Research at Cardiff University. Dr Peters explained how genes linked to MND function in cells of the brain. Providing some context to the wider research environment, Dr Nick Cole, our Head of Research, spoke about the development of the UK MND Research Institute, and new and emerging treatments.

The Minister for Health and Social Services, Eluned Morgan, who has been personally affected by MND, said: "I'm really pleased that as the Welsh Government, we have been able to be involved and be supportive of this. We are in a partnership with organisations which are trying to do their very best in this field including universities, charities and societies who are committed to this and most importantly patients."

The Minister closed the event by concluding: "What we have learnt tonight is that there is hope, there is a future and there is some light on the horizon. This has not been the case for those living with MND for decades and decades."

Senedd Members from across the political spectrum supported the event which was also attended by members of the MND community, volunteers, the South Wales MND Care and Research Network, NHS Wales staff, other charities and colleagues from Health and Care Research Wales.

Parliamentarians representing MND in Westminster

At the All-Party Parliamentary Group (APPG) Annual General Meeting in March, the group was successfully re-established for another parliamentary session.

Over 20 cross-party MPs and Peers attended the meeting. Andrew Lewer MBE MP, was re-elected as Chair and 10 Vice-Chairs were confirmed in post. The re-establishment of this group ensures that those living with and affected by MND will continue to have a strong voice and representation in Westminster.

During the meeting the parliamentarians heard from Professor of Neurology and Complex Disease Genetics Ammar Al-Chalabi on the latest advancements in MND research. Professor Al-Chalabi shared three exciting emerging treatments and the progress being made by the new UK MND Research Institute. This included the promising results being shown in trials for new drugs Tofersen and Interleukin 2 (IL-2,) and what hope they provide to the MND community.

Professor Al-Chalabi shared how the Government funding that's been released so far is being accessed by researchers, and what more parliamentarians can do to help ensure the remaining £20million from Government is released in a streamlined application process. The group will next meet in November.

From left to right: Sian Guest, Public Affairs Manager for Westminster and Devolved Nations, Eluned Morgan MS for Heath and Social Services and Millie Jenkins, Senior Policy and Public Affairs Adviser for Wales

"Lifelong friends" to the MND community

Two very special ladies are marking 30 years of dedicated service to the MND Association. Both personally touched by MND, they wanted to do whatever they could for others facing the same diagnosis.

Powered by this motivation, volunteers Janine Borny and Rosemary Rockett have stood by the side of those living with MND in their local communities, for more than three decades.

Janine joined the Jersey Branch of the Association in 1992 after her mum died of MND. Margaret McGovern, Branch Chair, explains how she soon became the heart of the local branch. "Janine has worked tirelessly to ensure the needs of people living with MND and their families were appropriately assessed and addressed. Her sensitivity, compassion and understanding has helped to lessen the isolation and distress felt by many. Families she's supported always tell me she's become a lifelong friend. We all see and feel her contribution, even if she doesn't realise the difference she makes to our community."

When Rosemary Rockett's brother died of MND she knew she had to do something. A woman with many skills she soon began to use her talents to support the Southampton and Winchester group. A keen baker, Rosemary's 'legendary' cakes started to build a reputation at coffee mornings and parties. Rosemary has supported many families over the years making a huge difference to them during their darkest times. Dawn Pond, Area Support Co-ordinator at the MND Association said: "Rosemary is always happy to try new things out if it means people with MND will receive the best care. I honestly don't know how the Southampton and Winchester Group would have survived without her."

Janine Borny with fellow volunteers

Rosemary Rockett (pictured left)

Coronation champions

Three MND Association volunteers have been recognised by Their Majesties The King and The Queen Consort as Coronation Champions, as part of the official Coronation celebrations.

Tracy Sanderson, Sue Starkey and Alex Millard were three of the 500 volunteers nationwide awarded the prestigious title. While Tracy and Sue were invited to celebrate at the Coronation Concert at Windsor Castle, Alex attended a garden party at Buckingham Palace.

Tracy, an Association visitor (AV), chose to volunteer for the Association after her husband died of MND seven years ago. Tracy said: "It's an honour to be named a Coronation Champion. At the West Yorkshire Branch, we work hard to support our members living with MND and all those connected to them, and to raise awareness of this dreadful disease."

Like Tracy, Alex is also an experienced AV. She was nominated because of her tireless energy to go above and beyond, to make sure everyone affected by MND in Bristol and Bath are supported. Alex said: "I volunteer because of the inspirational people I meet and being able to make a small difference to their lives. It makes volunteering rewarding and so worthwhile."

Having been involved with the Association for 20 years, branch secretary and treasurer Sue was recognised for being integral to the running of the West Yorkshire Branch. Speaking after the Coronation concert, Sue said: "It was truly amazing, what a fabulous atmosphere. Dancing and singing at our seats along with fellow Champions. The memory of the whole evening will stay with me for a long, long time."

Sue Starkey (pictured right) and sister-in-law Pauline

Tracy Sanderson

Alex Millard

"I'm still me"

Raising awareness of MND

After months of uncertainty over the cause of her speech difficulties, Yvonne Johnson, a mum of three working for a local authority in London, was eventually diagnosed with MND in May 2021.

Since then, Yvonne has experienced first-hand how people from different cultures react to her MND, and how it makes some very uncomfortable. She's determined to not only raise awareness of MND, but also how different cultures approach the condition.

Yvonne said: "Culturally, my family express ourselves in different ways – we're more dramatic, we're louder, we're just more. On one hand, the Caribbean side of my family are quite open to talking about my MND. Before I explained my diagnosis to friends and family, they have said to me that they thought I was tipsy when I've spoken to them. On the other hand, my family don't like to talk about sickness.

"When I speak to them, it's easier to tell them that I have a condition that affects my speech, rather than go into detail about MND. We don't always know why a person is sick, unless we are close to the family. When someone dies, we try to be discreet about asking the reason for their passing. Culturally we are very guarded about anything personal.

> **Different cultures' lack of awareness makes me feel like they're behind on their understanding of MND and how I can still live life with it. Some communities feel embarrassed by MND. We need to change that.**

"When I was in Barbados for my mum's funeral, I saw how uncomfortable some people felt when I talked. If I'm tired, I don't have the energy to talk, and, when I do talk, I sound drunk. I'd talk to people in the shops, but noticed they'd stop me talking and pretend they could understand me when they couldn't. It was clear it was because they were uncomfortable with how my speech sounded. They didn't want to hear me talking. It's like when I tell people I have MND, they think I'm going to die there and then. They forget, I'm still me.

"I decided I needed to let people know that there's a problem. I went on the MND Association's Facebook page and loved what I saw. There are some really positive people there, but I didn't see anyone who looked like me. I even asked my speech and language therapist whether there are any black people with MND in the UK, and she told me that there are.

"I looked up statistics, but they mainly come from America. I couldn't find anything in England, so I felt a bit isolated. I wanted to be able to communicate with someone from my background and my ethnicity, so I could ask them if they were going through the same thing culturally as me.

"I did a video to educate my family and friends about MND. I introduced myself, explained my condition, how I'm under represented and the challenges that we have culturally. I also explained that I will continue to be me for as long as I can. As well as the video, I've created social media accounts to raise awareness, and I've educated MND Association teams at their staff development day.

"Different cultures' lack of awareness makes me feel like they're behind on their understanding of MND and how I can still live life with it. Some communities feel embarrassed by MND. We need to change that."

"Clinical trials offer hope"

Lead MND Research Nurse Theresa Chiwe

Theresa Chiwera, Senior ALS (MND) Clinical Trials Manager and Lead MND Nurse oversees the delivery of clinical trials at King's College Hospital's MND Care Centre.

The Care Centre is part-funded by the MND Association and is a leading centre of MND research in the UK. During her eight years in the role, Theresa has worked on 20 clinical trials and research studies. In this time, she's seen a rapid increase in the number of trials focused on the disease.

She said: "So much is happening now in the field of MND research. We've gone from having one or two trials a year, to over seven at any given time. Studies are increasingly patient focused, often allowing remote visits or less frequent study visits, which increases the accessibility of clinical trials to patients.

"I've been involved clinically with two promising, potentially life-changing clinical trials in the past year. That's Tofersen - specifically for patients with the SOD1 genetic mutation, and the MIROCALS trial.

Lead MND Research Nurse Theresa Chiwera

"At King's we offer all our patients the opportunity to take part in research, whether a questionnaire-based study if a patient prefers this over a clinical trial, or the option to do a biobanking study which contributes to our understanding of MND.

"I know clinical trials offer hope to our patients and their families, and this is both rewarding and humbling. In my role I get to meet the most incredible people. Most of our patients are altruistic - they participate in these trials and research studies to help others. Patients know they could be on placebo treatment. Even if they're on the study treatment arm of these investigational drugs, there's no guarantee the treatment will be successful.

Researcher studying motor neurones

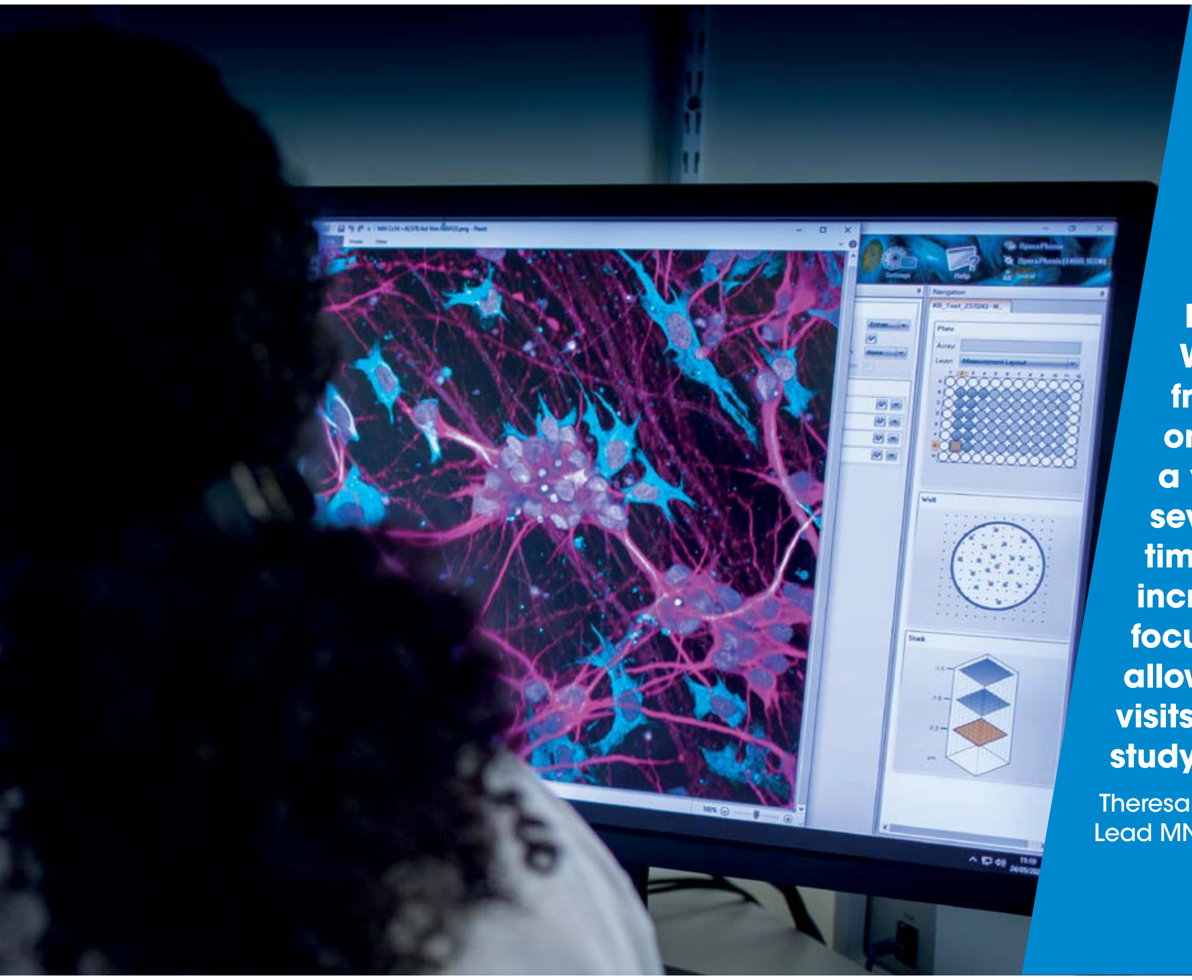
"When patients are on a trial, they have a dedicated and responsive clinical trial team and there's 24 hour cover in case a patient has adverse effects or concerns to report.

"Patients are also given flexible appointment scheduling, and if patients aren't able to attend clinic visits they are offered alternative remote visits if the study protocol permits, to make it easier for them to continue on a trial.

"Of course, our hope is always to find a cure. As part of that, we need to find biomarkers which can be useful for earlier diagnosis and targeting treatment. I'm also actively involved in looking for ways to improve the research service we provide, participating in projects to improve clinical care and quality of life, as well as support patients and their families.

Professor Ammar Al-Chalabi (left) and Dr Pablo Garcia-Reitboeck reviewing MND case notes at King's College Hospital MND Care Centre

ra discusses trial participation



> **So much is happening now in the field of MND research. We've gone from having one or two trials a year, to over seven at any given time. Studies are increasingly patient focused, often allowing remote visits or less frequent study visits.**
>
> Theresa Chiwera,
> Lead MND Research Nurse

"There's a lot to feel positive about. I'm confident in the commitment and dedication of the MND clinical and research community. Awareness and a determination to find a cure has definitely increased, helped by coverage in the media of events like the Rob Burrow Leeds Marathon and of high-profile individuals.

"The £50 million government bid is promising, as is the newly-founded UK MND Research Institute. This demonstrates vital collaboration by experts to find solutions, further developing and standardising MND research and clinical care for our patients.

"The MND community has also made a big impact. Quite simply we couldn't do research without funding, so the money raised by supporters and other funders helps us involve more patients in trials and increase our research portfolio. It's heartening to see how everyone is working together to get the cure we all long for."

Trial participation

Am I eligible to take part in a clinical trial?
There are specific criteria to meet before being considered for involvement in each trial. Your neurologist or the trial site lead will be able to discuss your eligibility in more depth. Before taking part in a trial, you will need to undergo a screening assessment to determine suitability.

What should I expect if I take part in a clinical trial?
Participants will take either the active drug or the placebo, a dummy drug. Trial therapies may be administered orally, via IV or lumbar puncture depending on the trial. Patients will be monitored throughout the trial. It's often possible for this to be carried out locally.

Once a trial ends, some have open label extensions meaning patients can continue to access the drug, but this doesn't happen in all cases.

Can I take part in a clinical trial near me?
The first step is to speak to your neurologist. Our Research Information team also has details of trials open for recruitment. You can contact individual trial sites for more information on how to take part.

Find out more on our website: www.mndassociation.org/treatment-trials

Support MND Carers campaign

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

Since the launch of our Support MND Carers campaign last autumn, more than 1,000 of you have written to your MP, backing our call for a government review of carer's assessment. That's led to 30 MPs taking practical action to improve support for carers. Now we are asking for your help to raise awareness of carer's assessments locally.

Pat and Miles Johnson

A carer's assessment is the first step to getting help, as **Kuai Peng Wong** found out when she completed an assessment as a carer to her husband KT, who is living with MND. Kuai Peng said: "My husband, KT, had a very good social worker who referred me for a carer's assessment. I had one in 2017 and they offered me things like respite and a grant to do whatever I wanted. And then another one was done over the phone during covid, where I received another grant. I recently arranged for another assessment to be done as KT's condition has changed since then."

Yet our report, published last year, revealed only 25% of carers of people with MND had received a carer's assessment or were in the process of having one. Like many carers of people with MND, **Pat Johnson** who cares for husband Miles, has found it hard to access adequate support. "I phoned up about a carer's assessment and they told me it could take weeks or even months before I got an assessment. They said I'd have to attend an appointment which could take up to two hours and they do not do home visits, meaning I would have to leave my husband at home. They've told me I will be put on a list, but I'm not optimistic that there is any support they can offer me."

Kin Tung Wong and his wife Kuai Peng

Our *Support MND Carers* campaign calls on the Government to launch a review into why carers aren't being assessed and why, when they are assessed, recommendations from the assessment are not being carried out.

MPs have taken actions including writing to the Health Secretary, Steve Barclay, submitting parliamentary questions and writing to local authorities in their constituencies highlighting findings from the carers report.

Influencing local support

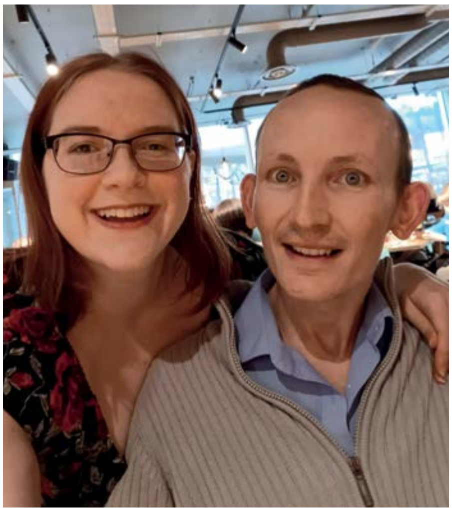
We're now asking you to focus on helping us to raise awareness of carer's assessments locally. You can do anything from sharing our carer's assessment infographic on your social media, to organising a meeting with your local councillors. Scan this QR code or visit www.mndassociation.org/supportmndcarers to see what you can do to make a difference.

Carers Week

Carers Week in June provided us with another opportunity to highlight the challenges unpaid carers face. At a roundtable with Minister for Social Care, Helen Whately, we discussed how we can work together to ensure carers are supported in the community. We also joined two MND carers, David and Kuai Peng at a roundtable event with Ed Davey MP, leader of the Liberal Democrats and Liz Kendall MP, Shadow Minister for Social Care.

Caring for the carers

While we continue to lobby and call on the Government to do more for carers, the MND Association supports MND carers through our range of award-winning information resources, grants programme and dedicated in-person and virtual support groups.



Mike and Zoe Sumner Welch

Zoe Sumner Welch received a carer's grant after her husband, Mike, who she met on Channel 4's *First Dates*, was diagnosed with MND. She said: "The MND Association gave me a grant which paid for most of my driving lessons, enabling me to get my test done, and now I can drive Mike around. Without that support, it would be a lot harder for us day to day."

Find all our information and support for carers, including information about the Carers Assessment, on our Carers Hub: www.mndassociation.org/carers

Derek turns his passion into fundraising pounds

Derek was 65 when he first picked up a golf club. Getting out on the green and enjoying a good course soon became a passion for Derek, now 88.

And for much of that time he's been using that passion for golf to raise money for the MND Association, after the disease devastated his family.

In May, Derek held his 13th golf day, organised in collaboration with the Cornwall Branch of the MND Association, with help from the St Austell Lions. The day was held at St Austell Golf Club and, with 35 teams teeing off, raised an impressive £5,600 to help support families affected by MND in Cornwall. For some of the teams, the golf day has become a key date in their diaries since 2008, and they never miss a chance to play.

Derek said: "This year's golf day was wonderful, everyone enjoys it and I always get really good feedback. People have been asking about next year's event already so that's all booked."

Alongside golf, Derek has fundraised by walking the Bodmin Lions 10 Tors and supporting a Vintage Car Rally for the MND Association. His dedication and determination to raise as much as possible on every occasion means he estimates he has raised around £150,000 to date.

> **I want to make people aware of how devastating MND is, and, in some way, offer some comfort and hope to others. All the money I've raised has been able to help support other families in Cornwall.**

Raising awareness of MND is truly where Derek's passion lies. Over the years, he has given numerous talks about the disease and raised awareness through his work with the Bodmin Lions, of which he has been a member for 23 years. Spurring Derek on is the knowledge of how difficult it is for people who have been diagnosed and those who love them and care for them.

Derek (pictured second from left) and his son Andrew (centre)

Derek said: "In 1984, my first experience of MND was when my sister-in-law died on 15 March from the disease, having lived for two years from diagnosis. I was not aware at that time there would be any further experience with the disease. How wrong I was.

"In 2005 my first wife (from whom I was divorced) was diagnosed with MND. She was followed in 2006 by my middle son Neil, also diagnosed. My son Neil, died on 6 March 2007 and my first wife died on the 31 March 2007. I agreed to donate my son's spinal cord and brain for research, and, in June of 2008, was informed that the disease was familial and my remaining sons and my grandchildren would be at risk. This sadly has turned out to be the case. On the 3 February 2023, my youngest son Andrew died from MND. His ashes were scattered on Porth Island in Newquay, alongside his brother Neil. Porth beach was where many happy hours were spent with friends and family.

"After my experience in 2007, I decided to devote much of my time to raising funds to help those who were suffering from this awful disease, which also impacts on family and close friends. I do what I do because I want to do it. I want to make people aware of how devastating MND is, and, in some way, offer some comfort and hope to others. All the money I've raised has been able to help support other families in Cornwall.

Golf Day (Derek pictured right) with fellow golfers

Happier times, Derek with his young family

"I think the best thing about the golf days is that we have raised more awareness of MND. I also decided to become a member of the Cornwall Branch committee to devote my time to help those in Cornwall affected by this disease. I've given talks on MND to Rotary Clubs, Lions Clubs, Young Farmers and even a doctors' surgery.

"I feel that this was to be a purpose in my life and I've been blessed with the wonderful support of my lovely wife Brenda."

London Marathon

Firefighter runs in full kit

When firefighter Garry Maybanks signed up for his first ever marathon, he decided to opt out of the usual running vest and instead run the marathon in his full fire kit and breathing apparatus, weighing over 20kg.

A firefighter for Greater Manchester Fire and Rescue Service, Garry wanted to challenge himself in tribute to a beloved family member, Wendy Esposito who recently died from MND. Garry said: "Wendy was an extraordinary woman who had such a massive impact on the lives of everybody who was lucky enough to know her."

Garry raised an incredible £4,000 to fund care and research into MND. But for Garry, taking on the London Marathon was not just about raising money, it was also an opportunity to celebrate the life of Wendy.

"I've always wanted to run the London Marathon, so when the opportunity arose to run for the MND Association and not only raise some much-needed funding but also celebrate the life of Wendy, it was perfect for me. I wanted to go a step further and complete it in my full fire kit and breathing apparatus, to test my physical and mental capabilities.

"Crossing the finish line, I felt extremely proud to be part of such a special event for her and for all the other brave people who've had their lives affected by MND."

Garry joined 235 MND Association runners who together raised a record-breaking £700,000 that will help fund our ground-breaking research into MND, as well as co-ordinated care for those living with the condition. Every one of our runners has their own inspiring story for taking on this epic challenge. Thanks to everyone who got up early to line the streets all the way to the finish line to cheer our runners home including members of the South London Branch at mile 21 check point.

If you would like to be part of #TeamMND for the 2024 TCS London Marathon please contact fundraising@mndassociation.org

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Meet the professionals: Specialist nurses

Specialist nurses work in a wide variety of acute and community settings, specialising in a particular area of practice from mental health to community nursing. The work of a specialist nurse can help to reduce unnecessary hospital admissions and shorten waiting times.

MND specialist nurses usually work in an MND care centre or network, a hospital or a hospice. Their role is to provide ongoing support to people with MND, their families and carers by offering specialist information, practical and emotional support, and guidance on managing the symptoms of MND. They may offer home visits, clinic appointments or a combination of both.

MND specialist nurses work as part of a multidisciplinary team to provide high-quality, patient-centred care. They may carry out the person with MND's initial assessment to establish their needs and put a plan in place, co-ordinating their care with the wider multidisciplinary team.

MND specialist nurses often act as a single point of contact for people with MND, offering information and advice, and signposting them to other support and services. Some specialist nurses also work with other health professionals, offering education and guidance to increase their understanding of MND.

Kathryn Barber, MND Specialist Nurse and MND Co-ordinator, East Suffolk said: "An important part of my role is to enable patients, giving them choices and some control in what can feel like an otherwise out of control disease progression. At present, the outcome cannot be changed, but symptom control can be improved, quality of life can be the focus, and patients can have an advocate, and therefore continue to have a voice. Honesty is at the heart of my practice which I hope helps those I support to feel listened to and understood, and able to put their trust in me."

Accessing support from a specialist nurse

The NICE guideline on MND assessment and management recommends that a specialist nurse should be a core member of the MND care team. However, this is not always the case. Ask your MND care team if there is a MND specialist nurse in your area, and how you can link into their support.

Kathryn Barber, MND Specialist Nurse and MND Co-ordinator, East Suffolk

Online module for nurses

We have worked with the Royal College of Nursing (RCN) to develop a resource to support nurses in the care of people with MND. This course is designed for registered or student nurses, health care assistants (HCA) or assistant practitioners working in any health care setting or specialism.

It can be accessed at https://rcnlearn.rcn.org.uk/Search/MND-Resource

Act to Adapt campaign

First Action Week raises awareness

Our first *Act to Adapt* Action Week took place in April raising awareness of the importance of home adaptations for people with MND.

As MND progresses, home adaptations become both vital and urgent so people can live in a safe and accessible home, without experiencing long delays and high costs.

To highlight this issue, we shared the experiences of Alex Herd, KT Wong and Sam Hayden-Harler who are all living with MND and have all had home adaptations, on our social media channels. This prompted many of our supporters to share their own experiences of home adaptations.

Our *Act to Adapt* campaign calls on councils in England to use their discretionary powers to ensure they are meeting the needs of people living with MND in relation to accessible housing.

We would like to thank our branches and groups for helping to fund the Act to Adapt campaign through the 2022 Chief Executive's appeal.

You can find out more about our *Act to Adapt* campaign and Action Week at www.mndassociation.org/get-involved/campaigning/take-action/act-to-adapt

Sam Hayden-Harler and his husband James

> **I want to be independent for as long as I possibly can. If we need to adapt things like the wet room, I want to be able to stand under the shower and not be reliant on someone else.**
>
> Sam Hayden-Harler

> **I have a gantry hoist to adjust my position in the wheelchair. It definitely helps the carers to transfer me from bed to wheelchair to lounge then back to bedroom with ease.**
>
> KT Wong

KT Wong

Alex Heard and his husband Craig

> **Ramps are important.. we need to make the back door level access as well. Our bathroom needs to be turned into a wet room – it's hard already getting out of the bath or shower.**
>
> Alex Heard

Read more about Sam, KT and Alex's stories at www.mndassociation.org/actionweek

“One of the best days of m

Joy. Exhilaration. Exhaustion. Delight. Pride. Elation. Pain. The finishing line of the inaugural Rob Burrow Leeds Marathon was the site of so much emotion. Every face etched with its own 26.2 mile story.

For some it was about the incredible fundraising effort for the MND Association, and other charities. For some it was about the personal achievement, marking the culmination of months of gruelling training. For some it was about being part of something that mattered.

For all the runners and the tens of thousands of people who lined the route to and from Headingley Stadium, it was a day to remember.

Sea of blue and orange

More than 15,000 runners signed up to take part in the marathon and half marathon on Sunday 14 May. The event was the brainchild of our patron Kevin Sinfield OBE, who wanted to give the MND community a challenge to be part of in the name of his team mate and friend who is living with MND.

As one of the primary charity partners, the MND Association was represented on the hilly course around Headingley and Otley by more than 2,300 runners, creating a sea of blue and orange running vests.

The entire course was lined with supporters with three dedicated MND Association cheer points at miles four, 16 and 17 boosting the flagging runners.

“It shows the love and care for me”

Veteran runner Andy Roberts donned his Association vest for the race. He said: “I’ve never smiled so much doing a marathon. I loved the crowds, they were just amazing. There were lots of high fives and grabbing sweets. It was absolutely fantastic.”

There were moments to savour – from the applause for people with MND at the start, to the banners, balloons and generosity of strangers around the course.

But for many, the image that will remain was that of Kevin stopping short of the end point in a busy Headingley Stadium, to gently lift Rob from his wheelchair and carry him across the finish line, planting a kiss on his cheek as he did so.

After the event Rob shared his feelings at being pushed round the entire course by Kevin and his team, before his triumphant return to the Leeds Rhinos’ Headingley Stadium. He said: “The marathon was one of the best days of my life. It was a great day and to be carried in over the final few yards was incredible. And how many people will be jealous of the smacker on the cheek [from Kevin]. It just shows the love and care for me and I have the same for him.”

To date, MND Association runners taking part in the Rob Burrow Leeds Marathon have raised an astonishing £1.6 million. Entries are now open for the 2024 event taking place on Sunday 12 May.

y life”

> “
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> **The marathon was one of the best days of my life. It was a great day and to be carried in over the final few yards was incredible.**
>
> Rob Burrow MBE

New science discovery could lead to nasal spray treatment

Recent research from the University of Sheffield, led by Professor Guillaume Hautbergue, has discovered a potential new method of preventing nerve cell death in the most common genetic form of MND.

The findings could, with further studies, lead to the development of a potential therapy for C9orf72 MND, which affects around 5-10% of people with MND.

The mistake in the C9orf72 gene causes the genetic instructions to be wrong and leads to the formation of toxic proteins. The researchers found a way to reduce the production of these toxic proteins using a small drug-like compound. This potential treatment decreases the movement of the faulty instructions to the protein factory of the cell. This means that fewer toxic proteins are made and cause less damage to motor neurones. The researchers suggested that, in the future, this possible treatment could be administered by a nasal spray. Further research is needed to confirm the findings and test whether a nasal spray is possible.


Professor Guillaume Hautbergue

Professor Guillaume Hautbergue is also the lead researcher on a project funded through our partnership work with LifeArc. In new research, he is looking to further develop another way of targeting the C9orf72 gene mutation. It is hoped that this research will enable more testing of this therapy and lead to the potential gene therapy being tested in a clinical trial.

Find out more about this project at www.mndassociation.org/srfs1

Chair's message

As I come to my first anniversary as Chair of the Association, I am pleased to be able to reflect on a year of significant progress.

Our new Chief Executive Tanya Curry and her team have quite literally hit the ground running with the magnificent effort of supporting more than 2,300 of our runners at the Rob Burrows Leeds Marathon, one of a number of landmark events and activities which have continued to boost the profile of MND.

Earlier this month the Association hosted its 38th Annual General Meeting (AGM). A very positive financial position was reported by our Honorary Treasurer Jim Marshall along with an overview of a record level of spending on research and care. We saw an unprecedented number of candidates standing for election to join our Board of Trustees. We know this presented a challenge to members, but we hope you will agree it was also a vote of confidence. Look out for an introduction to our new trustee in the autumn edition of *ThumbPrint*.

As you know from our spring issue, we had hoped to hold our first in-person AGM, post pandemic, but in the end we made the decision for it to remain a virtual event for one more year. I understand the disappointment this may have caused but can assure you that with wider consultation of our members, we will bounce back with some exciting activities and events in 2024.

Finally, I'd like to thank everyone for their support in marking Global MND Awareness Day on 21 June. The challenge of working to rid the world of this most terrible of diseases continues but, with your continued support and enthusiasm, we have clear shoots of hope in sight.

Overcoming barriers
to build supportive communities

North West Wales is widely considered the heartland of the Welsh language. Welsh is the day-to-day language and is spoken and understood by many.

To overcome any barriers and to build warm welcoming communities, our North West Wales Group funds two bilingual support meetings. These meetings offer a place where people affected by MND can come together in a relaxed, informal environment, have a cuppa and a chat in both Welsh and English.

The meetings are supported by volunteers who are a mix of Welsh, English and bilingual speakers. All those who attend the group, whether they have Welsh or English as a first language, can speak to a volunteer who shares their first language. Being able to speak freely in a chosen language provides both reassurance and comfort, and boosts emotional connection.

Jen Roberts, North West Wales Group contact explains the importance of this. "It's really nice for people to be able to talk about things in their first language, and then feel able to change to a different language as part of the wider group discussion. We want to be a welcoming place where people can share their thoughts, concerns or experiences free from any barriers or communication challenges."

Eirlys attended her first meeting after being diagnosed with MND, and was made to feel very welcome. She said: "It was a very positive and informative afternoon which I thoroughly enjoyed. I came home with a brighter outlook for the future and I'm already looking forward to the next meeting."

Meetings are held in Bangor and in Nefyn on the Llyn Penninsular. Anyone affected by MND is welcome to attend. For more information please contact Jo Cunnah, Area Support Co-ordinator, jo.cunnah@mndassociation.org or on 01604 800628

> **It's really nice for people to be able to talk about things in their first language, and then feel able to change to a different language as part of the wider group discussion.**

Members of the North West Wales Group

Goresgyn rhwystrau
i adeiladu cymunedau cefnogol

Mae Gogledd Orllewin Cymru yn cael ei hystyried fel cadarnle'r iaith Gymraeg. Yn yr ardal wledig hon, y Gymraeg yw'r iaith o ddydd i ddydd ac fe'i siaredir a'i deall gan lawer.

Er mwyn goresgyn unrhyw rwystrau ac adeiladu cymunedau croesawgar cynnes, mae ein Grŵp Gogledd Orllewin Cymru yn ariannu dau gyfarfod cefnogi dwyieithog. Mae'r cyfarfodydd hyn yn cynnig man lle gall pobl sy'n cael eu heffeithio gan MND ddod at ei gilydd mewn amgylchedd hamddenol, anffurfiol, cael paned a sgwrs yn y Gymraeg a'r Saesneg.

Cefnogir y cyfarfodydd gan wirfoddolwyr sy'n gymysgedd o siaradwyr Cymraeg, Saesneg a dwyieithog. I'r rhai sy'n mynychu'r grŵp, boed y Gymraeg neu'r Saesneg yn iaith gyntaf iddynt, byddant yn gallu siarad â gwirfoddolwr sy'n rhannu ei iaith gyntaf. Mae gallu siarad yn yr iaith sydd fwyaf cyfforddus i'r rhai sy'n mynychu'r grwpiau, yn rhoi sicrwydd a chysur, ac yn hybu cysylltiad emosiynol.

Mae Jen Roberts, Cyswllt Grŵp Gogledd Orllewin Cymru yn egluro pwysigrwydd y gallu i siarad ym mha bynnag iaith yw eich iaith gyntaf. "Mae'n neis iawn i bobl allu siarad am bethau yn eu hiaith gyntaf, ac yna teimlo eu bod yn gallu newid i iaith wahanol fel rhan o'r drafodaeth grŵp ehangach. Rydyn ni eisiau bod yn lle croesawgar lle gall pobl rannu eu meddyliau, eu pryderon neu eu profiadau heb unrhyw rwystrau neu heriau cyfathrebu."

Mynychodd Eirlys ei chyfarfod cyntaf ar ôl cael diagnosis o MND a fe wnaeth y grŵp deimlo'n gartrefol iawn iddi. "Roedd yn brynhawn cadarnhaol ac addysgiadol iawn a fwynheais yn fawr. Fe ddes adref gyda rhagolygon mwy disglair ar gyfer y dyfodol ac rwy'n edrych ymlaen yn barod at y cyfarfod nesaf."

Cynhelir cyfarfodydd ym Mangor ac yn Nefyn ym Mhen Llyn ac mae croeso i unrhyw un y mae MND yn effeithio arnynt i fynychu. I gael rhagor o wybodaeth cysylltwch â Jo Cunnah, Cydlynydd Cymorth Ardal jo.cunnah@mndassociation.org 01604 800628

The Health and Disability White Paper
Our response to the proposals

The MND Association is one of the charities invited to help shape the Department for Work and Pensions (DWP) plans for future legislation around employment support for people with disabilities and health conditions.

The DWP has published its Health and Disability White Paper, setting out proposals. And, as one of the charities and organisations on the Engagement Board, the MND Association is now reviewing the information and providing input into the next stages.

The paper sets out a series of proposals which aim to ensure people can access the right support, and have a better experience when applying for and receiving health and disability benefits.

We welcome some of the proposals, including plans to remove the existing Work Capability Assessment for Universal Credit. This would mean there was just one health and functional assessment – the Personal Independent Payment assessment.

There is also a suggestion to test a Severe Disability Group for those with the most severe health conditions. These changes could reduce the administrative burden on people with MND by streamlining the assessment process.

While we welcome streamlined access to disability benefits, we believe too much focus has been placed within the White Paper on enabling disabled people to return to work. Given the progressive nature of the condition, it's unlikely a person with MND will return to work once they've left. We are calling for more focus on ensuring those who leave the workforce indefinitely don't face financial hardship because of their condition.

Department for Work & Pensions

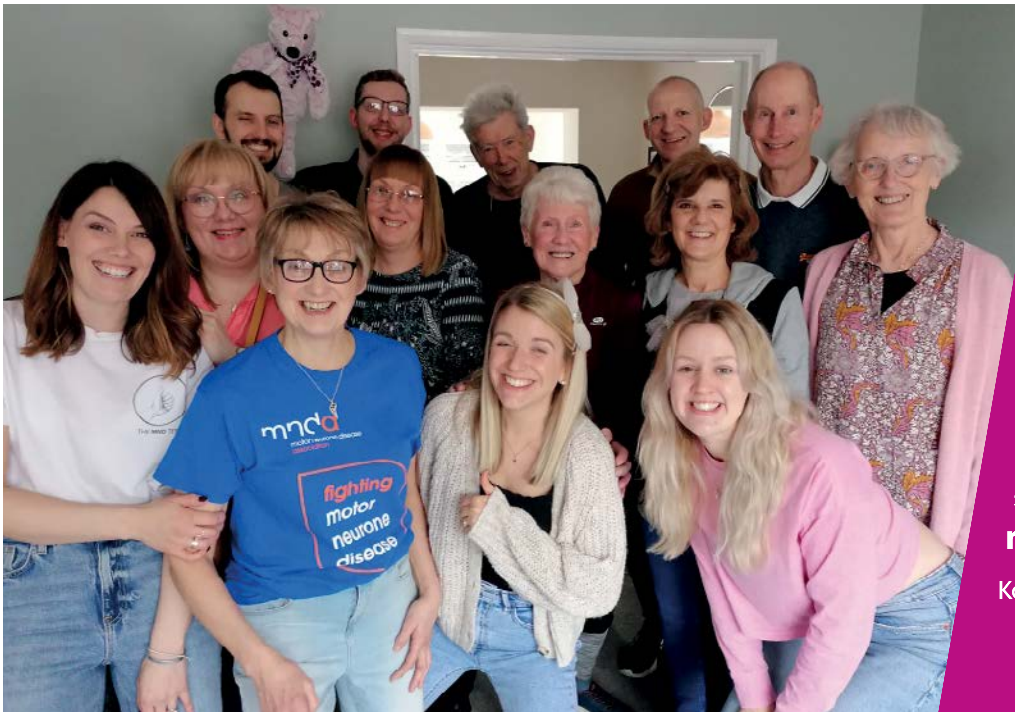
We know many people living with MND will, at some point, need to access disability-related benefits and support provided by DWP. Our research has found that people with MND spend, on average, £14,500 a year to meet the costs of living with and managing the disease. Entitlements provided by DWP can be a vital source of financial support.

The proposed changes in the White Paper would require legislative change.

That is not expected to be completed in this parliament and could take up to three years to be rolled out.

As members of the Engagement Board we will ensure the experiences of people affected by MND are fully represented, and help to identify potential challenges this legislation could create.

Creatives showcase their talents
Supporters raise over £60,000


Kate hosted a coffee morning for family and friends where she sold everything she had made during her makeit! challenge and raised £1,165

> **“Signing up for the *makeit!* challenge was really therapeutic, it was such a positive experience. I decided to host a coffee morning at home to sell everything I had made during the month.**
>
> Kate Johnson

Our *makeit! in March* Facebook challenge bought together more than 1,000 creative supporters who used their skills to raise an impressive £60,000. People were encouraged to get involved in any form of creative activity, across the month, from knitting to baking, crafting to crocheting and painting.

They raised money by either selling their ‘makes’ or getting sponsored for spending time crafting every day throughout March. The flexibility of the challenge allowed everyone to showcase their talents and contribute to the cause in their own unique way.

Louise Cleaton took part to show her support for her brother Mark, who is living with MND. Louise said: ”Mark is fighting with every ounce of his energy and has made it his mission to spread awareness, raise funds and support others with MND. We are super proud of him. Mark, his friends and our community, who are all amazing, have completed many challenges, bike rides, mountain hikes, marathons and rugby matches, all too physical for me. I was at a loss as to how I could participate and then this challenge was announced, and I knew it was for me.

“The *makeit!* challenge came along at just the right time. Perfect for me to finally contribute to raising funds towards MND research into a cure for this devastating disease. This challenge has restored my passion [for sewing] and even pushed me to try new projects which I’ve thoroughly enjoyed. The response has been overwhelming, people have been so generous and caring.”

Kate Johnson joined the challenge after her sister, Mandy, died from MND. She said: “I really struggled mentally after my sister’s short fight with MND. I was principle carer for Mandy, along with her daughter and best friend. It was so difficult watching a strong person deteriorating mentally and physically. After she died, I found going back to work really difficult.


Louise Cleaton

“Signing up for the *makeit*! challenge was really therapeutic, it was such a positive experience. I decided to host a coffee morning at home to sell everything I had made during the month. I had massive support from family and friends and raised a staggering £1,165.”

As an extra incentive, participants who raised over £100 were eligible to claim their own *makeit!* tote bag. The £60,000 raised by our creative crafters is enough to fund a full-time care co-ordinator at one of our MND Care Centres for a whole year.

Like other Facebook challenges, *makeit!* fostered a strong sense of community. Makers shared their progress, offered encouragement, and provided inspiration to one another through the dedicated Facebook group.

Find out about our upcoming Facebook challenges by visiting www.mndassociation.org/facebookchallenge

Partnerships that power our work

Fundraising as 'charity of the year'

Stonegate canoe challenge team

The MND community is the most powerful asset we have in fighting the disease. A vital part of that community is our corporate partners, organisations that choose to support us, often over months or even years.

Often the motivation for a business to support us comes from personal experience. Last year **Stonegate Group**, the UK's largest pub company, selected the MND Association as its charity of the year because one of their colleagues has the disease. Staff have thrown themselves into fundraising, from baking cakes to canoe challenges and sponsored car washes, so far raising over £250,000 towards their £400,000 target.

Talking about the motivation to join the fight against MND, Tim Painter, HR Director at Stonegate, said: "The MND Association was nominated by a colleague as it was close to their heart, and it's been amazing to see so many of our teams and guests getting behind our fundraising. The MND Association has been with us every step of the way, we couldn't have asked for a more supportive partner."

Two years ago, we embarked on a three-year partnership with **Toyota (GB) plc** to raise £300,000 to fund our support grants programme. Like Stonegate Group, for Toyota the partnership is personal, as Agustín Martín, President and Managing Director, Toyota (GB), said: "We decided to work with MND Association after a consultation process with our staff, many of whom had worked alongside a dear colleague who sadly died from MND, so it's a cause that's very important to us and we are really pleased to be supporting it. We hope our fundraising will continue to give a significant boost to the support the charity can offer to people living with the disease and to invest in research that will increase understanding of the disease, develop treatments and ultimately a cure."

Ollie Bearman undefeated in Baku, Azerbaijan

We often talk about the need for urgency – how MND won't wait and neither will we. Speed is at the heart of our partnership with **Aventum**, which is a partnership linked to a remarkable up and coming young racing driver, Ollie Bearman. As Ollie blazes a trail in the Formula 2 racing championship, Aventum has pledged to donate £2,000 for every podium finish he achieves this season. In April, Ollie demonstrated his racing prowess by winning every race, including setting the fastest lap and securing pole for the feature race in Baku, Azerbaijan. Two months later, he secured his second first place finish in the feature race, at Barcelona.

Linking services to support

While some corporate partnerships create opportunities for staff involvement, other businesses pledge to donate money from the sale of products or services. Fancy watching Ed Sheeran in Vegas or getting your hands on two VIP tickets to The Masters? One of our corporate partners can give you a chance to make that happen, while also supporting the MND Association. **VIP Volcano** is a competition website that specialises in VIP tickets and experiences. The company offers tickets and hospitality experiences to the biggest music, sporting and comedy events in the UK. VIP Volcano is donating a minimum of 10% of every ticket sold, as well as running special competitions where 100% of the funds raised will be donated to the MND Association.

Once again, the personal connection

Paul Jameson and David Setters who are both living with MND, raising a toast and funds from 50 Million Gin

If you work with or know a business who may be interested in joining the fight against MND, contact us on 01604 611888 or corporate@mndassociation.org

> **The MND Association was nominated by a colleague as it was close to their heart, and it's been amazing to see so many of our teams and guests getting behind our fundraising.**
>
> Tim Painter
> HR Director at Stonegate

is strong as Gary Holliday, Managing Director, VIP Volcano explains: "Our team have first-hand experience of how cruel this disease can be. Watching how it impacted our friend Wayne McNamara and his family, and the decline in his health was horrendous. There is no other charity that we wanted to work with, and just hope that with our donations and support, the MND Association can continue its incredible work to help find a cure, and support those affected by this terrible disease."

Another partnership that links their services to support is the **Liberty Group**, a family business providing modular and portable accommodation to organisations working remotely with no electricity or water. Back in August 2021, they started to raise funds by donating a hire contribution of £125 per week from one of their most popular products. So far they've raised over £11,000.

Greg Culshaw (centre) is joined by Agustín Martín, President and Managing Director of Toyota (GB) (left) and Jody Cundy (right) during his 24-hour bike ride fundraiser

The Liberty Group chose to support the MND Association in memory of Winston Malcolm Millard, who died 13 years ago from MND. Alex Jones, Group Managing Director said: "We are proud supporters of the MND Association. This charity is close to our hearts with the unfortunate passing of a family member to this devastating disease. Our goal in this project was to not only raise funds for the charity, but also to raise awareness."

Raising a toast to the MND community

When Paul Jameson, who is living with MND, visited Village Spirit Collective, a gin micro-distillery near Guildford around the same time the Government agreed to invest £50 million into MND research, the idea of a celebratory gin was born.

To Paul and his friends, partnering with the Village Spirit Collective to produce 50 Million Gin was the perfect way to thank all those who campaigned so hard to secure the funding. What's more £8 from every bottle is donated to MND charities.

Paul said: "50 Million Gin raises a toast to all those in the MND community who fundraise for MND causes, and to those who suffer from the illness with so much courage and strength. Partnering with the Village Spirit Collective, has given us the opportunity to raise money to support the work of the MND Association."

From gin to colourful pants – another product you can buy while supporting the MND Association. OddBalls is an underwear brand that specialises in comfortable, colourful underwear. The company has created a special range honouring MND Association patron and rugby legend Rob Burrow MBE. For every item sold in the Rob Burrow collection, Oddballs will make a donation to the MND Association, a win-win for everyone.

Corporate partnerships comes in all shapes and sizes, but they each power and strengthen our ability to fight MND. The more partnerships we secure, the greater our ability to fund vital research and support.

Rugby League rallies for Rob
and fundraises in Association colours

England women's team with the winning trophy

England Rugby League's men and women returned to international action in April for a fundraising game against France in aid of the MND Association.

The teams wore a new kit inspired by an England shirt closely associated with former player Rob Burrow MBE, who is living with MND, and incorporated the Association's colours and logo. The back of the shirt included Rob's own immortal words: 'In a world full of adversity, we must dare to dream'.

The Association also appeared on advertising boards, the LED screen and even on the ribbons of the trophies at the game which was held at Warrington's Halliwell Jones Stadium and broadcast live on Sky Sports Arena.

Rob and his family watched the game live from the stands, with his children Maya, Macy and Jackson having the opportunity to walk out the match ball for the men's match. Chris James, the Association's Director of External Affairs presented trophies to the winning teams, in which both England's men and women were victorious.

Donations to the Association were made through ticket sales and through purchases of the special replica shirts, as well as bucket collections on the day.

Clockwise from top left: Maya, Macy and Jackson bring out the match ball; The match trophy; England and France women's teams; Chris James and George Williams of the England Team

All photos: SWpix.com

What's Love Got to Do with It?

Lily James attends screening

Film and TV star Lily James attended a special screening by the North London Branch of her film *What's Love Got to Do with It?*.

The one-off event, held at the Phoenix Cinema in East Finchley, was followed by a Q&A session with Lily, chaired by BBC sports journalist Mike Williams.

Lily is a patron of the North London Branch while being known globally for her roles in a series of hit films including *Cinderella*, *Mamma Mia*, *The Darkest Hour*, *Baby Driver* and *The Dig*, as well as her appearances in TV classics such as *War & Peace* and *Downton Abbey*. Lily has personally seen the devastating impact of MND, with the death of her uncle Bruce in 2006, and is an active supporter of the MND Association.

Lily with members of the North London Branch

Lily James (pictured) made a guest appearance at a special screening of What's Love Got to Do with It? raising funds for the North London Branch where she is a patron.

"Tony would have loved it"

Charity ball supports MND

A charity ball held in memory of footballer Tony Hopper and attended by more than 200 friends, family and former team mates, raised £20,000 for the MND Association.

The evening was a fitting tribute to the popular Carlisle United and Workington Reds footballer who did so much to raise awareness and funds through his MND Association Fightback Fund, before his death in 2018.

Ian Milburn and Sue Hopper (centre) with guests at the charity ball held in memory of footballer Tony Hopper

Event host Ian Milburn from IM Events said: "The total was sitting at just under £17,500, but we got another donation on the night to take it up to £20,000. That's well past expectations. It's a brilliant amount of money that will hopefully make a good bit of difference."

Ian thanked Tony's wife Sue, for her tireless efforts in organising the night and arranging raffle prizes. He said: "Sue was absolutely amazing from minute one, when we made the decision to do this. She's worked so hard and got some amazing raffle prizes. I can't stress enough how amazing she has been.

"Sue did a speech at the start of the night, where she talked about their time as a family, the 'Hoppy' memories they made, with a couple of videos. It really tugged at the heartstrings. The only disappointing thing was Tony wasn't there himself – he would have absolutely loved it. He was in everyone's thoughts throughout, as he always will be."

In May, more money was raised in Tony's honour when a group of his friends and family took part in the Rob Burrow Marathon in Leeds.

> **"**
>
> **The only disappointing thing was Tony wasn't there himself – he would have absolutely loved it. He was in everyone's thoughts throughout, as he always will be.**

The benefits of hydrotherapy
Weekly sessions have a positive effect

> **Tim really enjoys the sessions. It's a relaxing and calming experience for him.**
>
> Julie Le Mottee AV

Caption Tim Philips helped by Sophie Mears,therapist assistant, to exercise in the hydrotherapy pool

When Tim Philips enters the specially equipped pool at a care home in Jersey, the water supports his weight, the warmth allows his muscles to relax, and the soothing properties helps to ease his pain. Here he is free from his wheelchair, and is able to move far more freely than he can on land.

Tim has lived with MND for 14 years. Earlier this year, he was referred to the facility by the Jersey Branch of the Association. Since then, Tim's weekly trips to the pool have become a highlight of his week. Julie Le Mottee, Tim's Association visitor, explains the positive difference Tim's hydrotherapy sessions have made to him. Julie said: "Tim really enjoys the sessions. It's a relaxing and calming experience for him. But it's not just about what happens in the pool.

"Tim's limited mobility means he spends most of his time in his room at home, where he is looked after by carers. To have this to look forward to every week doesn't just boost his physical wellbeing, but his mental wellbeing too. He can relax, have some social interaction and enjoy a change of environment. We are lucky to have this facility in Jersey, and the Branch is always keen to refer people we think would enjoy and benefit from it."

Hydrotherapy (or water therapy) is an effective tool for improving the range of motion, flexibility and strength. It's often used by people with restricted mobility and those living with a wide range of conditions, including MND. Tim's body is buoyant in the water, so this form of exercise is less stressful on his joints, bones and muscles and, with the help of therapists, he's been able to enjoy a new freedom, standing and moving through the water.

"To anyone who might be considering hydrotherapy, it's important to get an individual assessment from therapists, who will then be able to identify and work towards realistic goals."

Hydrotherapy for neurological conditions may not be available in all areas, but it is worth asking your GP and health team if a referral is possible. Your physiotherapist can advise about which therapies and exercise routines would suit your needs.

You can read about hydrotherapy and other complementary therapies in our care information resource 6B - *Complementary therapies* at www.mndassociation.org/careinfo

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Pete and Little Grey Fergie's
fight against MND

Pete Burdass with Ted, his mascot and Little Grey Fergie

A tractor enthusiast from Scotland has driven a distance more than 1,200 miles in 12 days in his beloved 80-year-old tractor to raise money for the MND Association.

Pete Burdass and his 1949 Ferguson TED20 tractor, affectionately known as Little Grey Fergie, travelled from John O'Groats to Land's End in June raising more than £15,000 for the Association.

Instead of opting for a direct route, Pete's journey saw him stop at places of significance including his home town in Leven, East Yorkshire, and the old Banner Lane factory site in Coventry which originally built the Fergie tractor.

Pete was joined by a team of friends to make sure he got to Land's End, and despite a couple of breakdowns on the way made it safely to the iconic landmark ten minutes earlier than expected. Pete and Fergie received a warm welcome from the gathered crowd, which included the Association's Cornwall Branch.

Planning for the journey took Pete around two years, and he was inspired to raise funds for the Association in memory of his mum who died of MND on her 60th birthday.

Pete said: "It's been an epic trip and one that my mum would have totally got behind. It's been hard but the team have been great and we've had such great support from loads of people along the way. I'm really chuffed with how much money we have raised for the MND Association."

You can support Pete's fundraising by visiting: www.justgiving.com/fundraising/the-little-grey-fergie-challenge

Rugby legends inspire Cumbrian 100 mile challenge

The courage and determination shown in the face of an MND diagnosis by rugby legends Rob Burrow MBE, the late Doddie Weir, and most recently Ed Slater, inspired ex professional rugby player John Newell and seven of his friends and neighbours to raise funds and awareness.


John Newell third from left with members of his team. The full line-up of Prospect Proclaimers were John Newell, Kristina Thompson, Brian Irwin, Michelle Beverley, Mark and Elise Williams, Mike Weaver and Dan Marriott.

John, whose career spanned ten years, including a stint at Workington Town and Carlisle Border Raiders, was inspired to walk from his home in Prospect, Aspatria to Blackpool Tower. He, along with his fellow Prospect residents nicknamed the Prospect Proclaimers, whose ages range from 13 to 66, set off along the 100 mile route on 29 March completing the challenge in less than five days.

John said: "A few of us watched a TV programme about Rob and Doddie. I have known an ex-teammate who died from MND, so we just wanted to do something to help." Completing the challenge, John said: It was a hard walk but an experience none of us will forget. There was so much support and goodwill along the way. One day, when we'd been walking for 11 hours and everyone's feet were sore and blistered, Gary McKee – the marathon runner who ran a marathon everyday of 2022 - sent a personal video message of support which lifted the entire team." The Prospect Proclaimers have currently raised over £14,000 for the Association including offline donations and bucket collections.

To make a donation go to www.justgiving.com/John-Newall3

MND key messages updated

We have updated some of our awareness documents which contain key facts about MND and the MND Association.

These changes are as a result of our latest review process, which involves analysing each of our key facts about MND and checking to see if they reflect the latest MND research and other credible statistics. Many of the key facts remain as they were, with some receiving important tweaks to the wording.

The updated documents include our key facts infographic and a longer form key messages document, which may come in useful when referencing MND, the Association and the work we do.

You can find the updated documents on our website: www.mndassociation.org/about-us/who-we-are-and-how-we-work/mnd-key-facts

Keeping safe at home
Guidance now published

For many people with MND, leaving the house is a challenge. Decreasing mobility leaves them relying on support from both people and equipment to get around.

Tom, who is living with MND said: "We have 11 steps outside our house and I can't get out without assistance from a two-person ambulance team and an evacuation chair. It's a bit of a white-knuckle ride."

As people progress with MND, it becomes even more crucial to adapt to changing symptoms and ensure their home remains as safe and accessible as possible. This does not have to be about large adaptations, simply moving trip hazards or making small adjustments can make a big difference.

To help you stay safe in your home we've published guidance on our website covering a wide range of potential problems and solutions www.mndassociation.org/safety On the page you can access links to relevant organisations and reputable advice.

Asking for an assessment through adult social care services is a good first step to understanding your own needs and how they might be met. Further help is available from occupational therapists who can look at your home and suggest different ways of doing things, and physiotherapists who can advise on things like managing and preventing falls. These specialist services can also provide recommendations, advice, gadgets and technology.

It's worth considering what you would do in the event of a flood or a fire, and being prepared for power cuts, especially important if you're using assisted ventilation to support your breathing. Personal and home alarms, along with smoke and carbon monoxide detectors can provide peace of mind, while environmental controls can enable you to control facilities and equipment by remote control.

If you have any questions directly related to MND or Kennedy's disease, or about our support, contact our MND Connect helpline on 0808 802 6262 or email mndconnect@mndassociation.org

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Solo sailor in six-month sail around Britain

A doctor from Surrey is attempting an epic solo sail around Britain to raise money for the MND Association.

Dr Andrew Hill-Smith is sailing in a tiny dinghy with no cabin or support as part of a six-month journey, inspired by his friend and his uncle who both died from MND. Andrew set sail from Gosport in early April, hoping to raise £5,000.

Andrew said: "I've already capsized several times and broken the centre board in the first week. It's going to continue to be hard work. The boat might break. I might physically break. But I think emotional exhaustion will be the biggest problem."

The boat, a Laser, is less than 14-feet long. Andrew will be on his own for the duration of the trip and hopes to complete 10-50 miles per day, depending on the weather. If successful, Andrew will be only the third person to ever complete the round Britain challenge in a Laser.

Andrew was moved to attempt the feat after his uncle, David Shawcross and his friend, Guy Lidbetter died from the disease. Andrew knows it will be hard but the thought of raising vital funds will keep him going.

Andrew said: "Scotland will be tough as there are some massive tides and huge standing waves. But I'm motivated."

The Association's Director of Fundraising, Linda Allen said, "We are so in awe of Andrew's immense undertaking. What a wonderful tribute to his uncle and his friend to raise money for the MND Association."

If you would like to donate to Andrew's fundraising page visit www.justgiving.com/fundraising/laserroundtheuk3-mndassociation or follow Andrew's adventure at www.laseraroundtheuk3.uk or on YouTube via Andrew's YouTube channel.

Cost of living crisis continues

Our survey shows growing impact

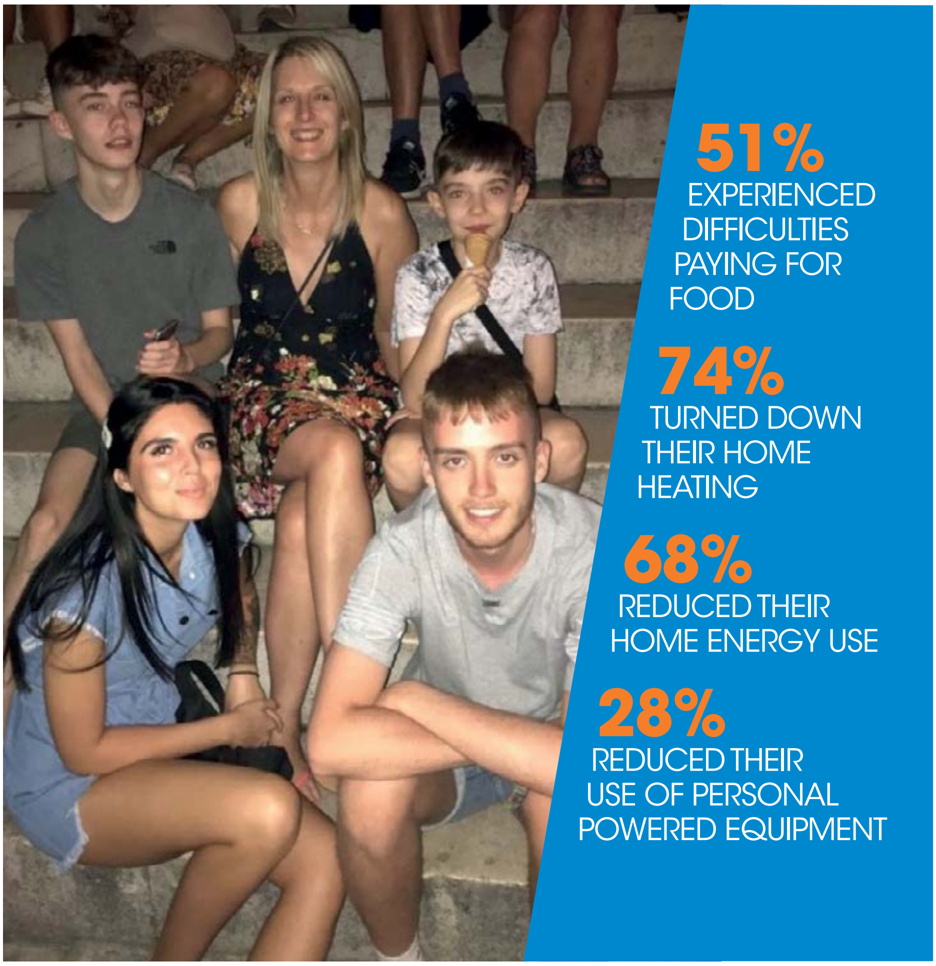
With energy bills having risen and surging food prices, the cost of living crisis continues to be a serious issue for many across the country. Our cost of living survey shows that the impact of the crisis on people with MND is particularly painful.

Over half of respondents (51%) reported their household experienced difficulties paying for food, home heating and energy over the last 12 months. Home heating and energy costs faced by people with MND are particularly concerning. Households affected by MND may spend more on electricity than average due to their need for personal powered equipment, such as wheelchairs, hoists and adjustable beds. We estimate that people with MND can spend up to £600 a year on electricity costs for charging and equipment use – this is on top of other household costs.

In our survey three quarters of respondents (74%) said they turned down their home heating and two thirds (68%) had reduced their home energy use. This is significantly more than the general population. Worryingly, more than a quarter (28%) of respondents also told us they have reduced their use of personal powered equipment in the last 12 months, in response to rising energy costs.

John Nelson

Our survey results suggest that the rising cost of living puts at risk not just people with MND and their household's financial stability, but their health and wellbeing too. In response, we will be campaigning to tackle rising energy costs, which we believe to be the most significant cause of this problem. We will call for additional support for people with MND, such as an Energy Social Tariff. This acts as a discounted energy bill and is targeted towards vulnerable people facing high energy costs.



51%
EXPERIENCED DIFFICULTIES PAYING FOR FOOD

74%
TURNED DOWN THEIR HOME HEATING

68%
REDUCED THEIR HOME ENERGY USE

28%
REDUCED THEIR USE OF PERSONAL POWERED EQUIPMENT

Jennie Starkey (pictured centre back), who is living with MND and her four children

We will also join forces with other charities to call for other measures to address the cost of living crisis. For example, we are backing the *Guarantee Our Essentials* campaign by the Trussell Trust and the Joseph Rowntree Foundation. This calls on Government to ensure Universal Credit covers the cost of life's basics such as food and bills.

If you'd like to get involved in our cost of living campaigning, please join our Campaign Network at www.mndassociation.org/campaignnetwork

For more information about *Guarantee Our Essentials* please see www.jrf.org.uk/report/guarantee-our-essentials

Find support

We've created a dedicated area on our website offering support, advice and signposting to further information. You can also find out more about the financial support the MND Association has available at www.mndassociation.org/costofliving

To talk to someone, please call our MND Connect team on 0808 802 6262. Lines are open Monday to Friday between 9am and 5pm, and 7pm to 10.30pm. Email: mndconnect@mndassociation.org

Inclusion spotlight:

We are aspiring to be a genuinely inclusive organisation, accessible to all who need us or want to support us. Part of this is recognising how changing our activities and processes can help the charity be more inclusive.

The West London and Middlesex MND Branch recently adapted its support meetings to be more inclusive, and in doing so has reached new supporters and seen an increase in its membership.

For many years the Branch held its support meetings in the same place and at the same time every month. Prior to Covid, they were well attended, but post Covid attendance started to dwindle, despite the on-line support groups continuing to thrive.

The Branch talked to its members and decided to change the day, format and venue to make it more accessible and easier for people to attend. The search for a new venue began. It had to be accessible by public transport, have parking and, be wheelchair friendly with good disabled facilities.

The Branch found a pub that had everything they needed and was willing to make a dedicated space available for the meetings. Since then attendance has boosted, meaning more people are able to access local support.

Proud to celebrate Pride

In June, we celebrated LGBTQ Pride Month, a month focused on people coming together in friendship, remembering queer history and pushing for equality. MND affects people from all backgrounds, and we want everyone to feel comfortable engaging with us and accessing our services, regardless of their sexuality or gender identity.

With a renewed boost in membership, increased engagement and a focus on inclusion, a West London and Middlesex MND Branch member approached the West London Queer Project, to raise awareness of MND. This inspired the Project to mark the start of Pride Month by hosting a joint-branded sponsored 10km Thames Park Walk in aid of the West London and Middlesex MND Branch, raising £2,158. The walk ended with a mini festival, which included star of BBC's RuPaul's Drag Race, Pixie Polite, who has fundraised for the MND Association before in memory of her gran.

Broadcaster and MND Association Ambassador Jeremy Vine supported the Thames Walk together with other VIPs and celebrities

Over 200 people joined the Thames Walk in June

To mark Pride Month we also launched a film on Global MND Awareness Day, featuring people living with MND alongside celebrity supporters including food writer Jonathan Phang, broadcaster Jeremy Vine, drag queen Pixie Polite and actor Peter Ash. The film aims to celebrate diversity and people's right to live without discrimination.

To watch the film scan this QR code or visit youtu.be/Un11BagV2Xk

Inclusion spotlight is our new regular *Thumb Print* column where we share stories showing how a person or part of the Association has gone a little further to be inclusive and accessible. If you've done something or know someone who has done something that's inclusive and accessible, please contact john.gillies@mndassociation.org

Jean's marathon challenge
to celebrate 93rd birthday

Jean walking her marathon with a little help from her great, great grandson, Joey

Many people approaching a birthday might plan a party, but 92-year-old Jean had other ideas. Instead of putting her feet up, Jean decided to walk the distance of a marathon during May, to support the MND Association.

Jean's fundraising inspirations were her sister-in-law, Kath who died in 2001, only a few weeks after being diagnosed with MND, and Rob Burrow MBE. Jean said: "My idea began when I watched a news item last spring about the Rob Burrow Leeds Marathon. This caught my attention as my dearly loved sister-in-law died of MND. So to hear of a young, fit rugby player and his family having to cope with this dreadful disease made me wish I could do something."

Jean with the teddy knitted for her by her late friend Brenda

Jean embarked on training walks to see what was possible, receiving encouragement from her Monday social club and accompanied by a teddy bear, knitted for her by her late friend Brenda. In May, Jean completed the challenge a few days after her 93rd birthday, clutching the special teddy wearing orange and blue.

Jean said: "Words are not enough to express my thanks for the support and encouragement I've received. I thought my first target of £500 was ambitious, but knowing that I have met the latest target of £1,777 with more to come, makes me both proud and humble. Proud that I've achieved my aim to support the work of the MND Association, and humble that so many people had faith in me."

You can support Jean's fundraising on her Just Giving page: www.justgiving.com/page/jean-craig-1679586321718

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.

£2,200

For Uncle David: Inspired by Kevin Sinfield's #Ultra7in7 challenge, six-year-old Beth took on her own 7in7 challenge, running 2km every day for seven days, raising over £2,200. Beth wanted to raise money to help find a cure for her uncle who is living with MND. Beth said: "I hope the money can be used to find a cure for people like Uncle David and to help their families." We're not the only ones who think she's awesome, Kevin himself donated £77.

£15,000

Marathon man: Simon Beacham has raised almost £15,000 since 2019 in memory of his friend and business partner Alan. Following his Hadrian's Wall three-day ultra-marathon challenge in February, Simon has also completed the Rob Burrow Leeds Marathon.

£1,800

Take two: When Liz Vickerstaff took on the West Highland Way last year, a fall prevented her from completing the challenge. Determined to raise funds in memory of her friends, Lynn and Ron who both died of MND, Liz returned to do the walk this year, not only completing it, but raising over £1,800 as well.

£1,230

Diamond Wedding Walk: Liz Perry and her husband John, celebrated their diamond wedding anniversary by completing a sponsored walk in memory of their son-in-law who died in 2016. Accompanied by their friends, the couple raised a sparkling £1,230.

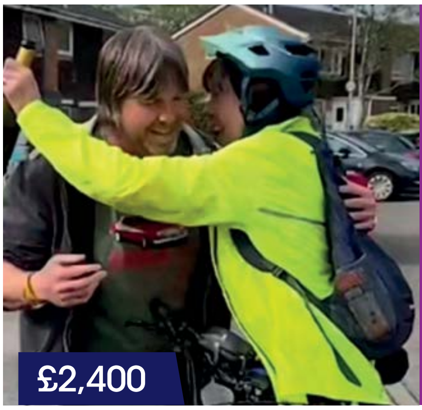
£4,220

127 miles for Grandad: Eight-year-old Scarlette cycled 127 miles over three days to raise money in the hope of finding a 'medicine' to help her grandad, and all the other people living with MND. Cycling the Leeds and Liverpool Canal, Scarlette raised a fantastic £4,220.

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**

Raising the roof
A day of music and dancing raised over £2,000 in honour of Sam Hayden-Harler, who is living with MND (and featured in our article on page 19). Sam's friend, musician Graeme Savage, came up with the idea of a music festival after hearing how raising money for the MND Association was one of the things on Sam's bucket list. Graeme said: "Sam came up with a bucket list that he wanted to achieve while he still could. One of the items was to attend the music festival, another was to raise money for the MND Association. We joined the two together so he can now tick both off his list."

Christmas crackers: Yvonne Heard, along with the local community of Hartland Village, held a Christmas cracker event raising over £14,300 for research into MND. The Hartland village community came back together to present a cheque to MND Association trustee Ian Lev who is living with MND.



Pedal Power: Admitting she's 'not the best cyclist' Justine Moseley set herself an epic challenge to cycle 200km to her brother's house, in tribute to her dad who died from MND. Justine credits good advice, 12 weeks of training and padded cycle shorts for helping her reach her destination, raising over £2,400.

Andrew's run: Andrew McGuire ran155 miles in 12 days from Greenwich to Bristol in rain, snow, mud and pain to fundraise for Campaign Against Living Miserably and the MND Association raising an incredible £8,630.

Making strides: Kim Beckett with her friends Rachel, Alison, Lisa, Lynette, Lesley, Nicky, Vicky, Jan and Christine formed a team, Making Strides for MND. The team completed a 50km ultra challenge at Windsor Racecourse raising over £6,600 in support of their friend Deb, who is living with MND.

Footie with friends
Graham Stirr, Adam Palmer and the Cornish football community gathered together for a special match in support of their friend Dean Mooney, raising over £3,600. After the match Graham and Adam swapped their football boots for trainers to take on the Rob Burrow Leeds Marathon.

Members' letters

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

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

Dear Editor,

When my husband, Alan, was diagnosed with MND, I started to write daily notes until the day he died. For over three years I worked on these notes, turning them into a book about our experiences of life with the disease.

Alan often said to me, "Life's good, it's the disease that's the problem" so *Life's Good* became the title. Writing the book hasn't been easy, but my motivation to inspire and help others living with MND, along with raising funds for the three charities that supported us (including the MND Association) has kept me going.

Neurologist Dame Professor Pamela Shaw wrote in her foreword the book is, 'really informative, as well as heart-rending'. I hope people living with MND find it useful too. I share how contacting MND Connect was the springboard to support from healthcare professionals, and how our local MND support group helped us to feel less alone.

The MND community is like a family to me nowadays. I hope you all have support on your journeys and please do contact me if my experiences can help in any way.

Hazel Carter

Network Groups – it's all change

Our network groups have changed their names. Embrace is the new name for our Black Asian and Minority Ethnic group and Pride is the new name for our LGBTQIA+ group. Both groups are open to people with or affected by MND, volunteers and staff, who are members, friends or allies of each community.

Email either of the groups if you would like to find out more. Pride@mndassociation.org and Embrace@mndassociation.org.

Christmas goodies

Although Christmas is still five months away, you can never start planning too early.

We hope you enjoy looking through our latest Christmas brochure enclosed in this issue. It's packed full of festive goodies for you, your family and friends. We've everything you need to help make your Christmas extra special this year, from wrapping paper and cards to the perfect stocking fillers for family and friends. And best of all, you can be safe in the knowledge that every penny of profit, together with any additional donations, will go towards improving the lives of all those affected by MND.

You can order your festive treats from 1 August either online at shop.mndassociation.org or by using the order form in the back of the brochure.

The MND Association is committed to minimising impact on the environment. Our potato starch mailing wrapper is derived from food industry waste and the energy used to manufacture it is less than that used to manufacture plastics. It is GMO free, doesn't contain any plasticiser and will decompose to nutrients for the soil in only a few weeks.

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.

Natalie Pike was only 38 with two young children when she was diagnosed with MND. This poem was written as she was trying to process her diagnosis.

In July 2013 I was handed my fate
A terminal illness at the age of 38
A young mum of two precious daughters
Motor neurone disease; a living torture

First to go was my confidence, then self esteem
I'm begging for this to be a bad dream
Anxiety and stress took over my mind
My life as I knew had to be left behind

I grieve for the person that I used to be
I've had to adapt to a life with MND
My muscles grow weaker and slow is my only speed
To avoid the falls; a wheelchair is a must, a need

Truly humbled by my family and friends
Their love and support has no end
Without them, I don't know how I would cope
With their help, I have strength and hope

Please give me a chance to turn my life around
To find the old me would be so sound
To feel positive would be a gift
And I would love to give my confidence a great big lift.

Hindi speaking support group

In April, we invited members of the Hindu community affected by MND to our first Hindi speaking support group to meet, talk and to hear their views about issues important to them.

We are pleased to announce a follow on session: **Tuesday 5 September, 11am.**

Please join us via Zoom (ID 834 5858 2753 Passcode: 572382)

MND Matters

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

Listen to episodes on our website at www.mndassociation.org/mndmatters or search *MND Matters* in your chosen podcast provider.

Episode 27 – Rob Burrow Leeds Marathon

This special episode takes you behind the scenes at the inaugural Rob Burrow Leeds Marathon. Hear from members of the MND community and why they were inspired to take part.

Episode 26 – What is MND?

Join Dr Nick Cole, the MND Association's Head of Research, for a mini episode as he explains the basics of MND and answers some of the most frequently asked questions about the disease.

Episode 25 – Wheelchairs

8 in 10 people with MND will need a wheelchair while living with the disease. Listen to Simon Aspray, a wheelchair user who has MND, and Maggy, a wheelchair therapist, part-funded by the Association, discuss the process of getting a wheelchair and the importance of accessing the right equipment at the right time to support changes in mobility needs.

About us

The Motor Neurone Disease (MND) Association

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

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

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

Social media

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

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MND Connect

Our MND Connect helpline offers advice, practical and emotional support and signposting to other organisations.

Open Monday to Friday 9am to 5pm and 7pm to 10.30pm.

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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