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Uniting communities at Manchester Pride 2023

On the cover: A drag artist celebrates Manchester Pride alongside people with MND, Association branch members, volunteers and staff taking part in the parade over August Bank Holiday.



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# Welcome

## from our Chief Executive

If you've opened this issue of *Thumb Print* without looking properly at the front cover, please turn back now. I love that photo, taken at Manchester Pride over August Bank Holiday. See more pictures on page 27.

A number of people with and affected by MND, branch members, volunteers and staff joined tens of thousands of LGBTQ+ people and allies to march together for equality – and met some colourful characters on route. The spectacular rainbow parade draws crowds from across the country.

We know MND can, and does, impact people from all backgrounds. Over the last couple of years in particular, we've really focused on how we can ensure all people with MND experience equity of services, support and care. There is still work to do, we know there are groups of people under represented in our MND community. But we're working hard to change that. By involving ourselves in events like Manchester Pride we're demonstrating in a really positive way that commitment.

And talking of commitment – I was delighted to attend our second EnCouRage event where I met an incredibly talented group of Early Career Researchers, who have committed to working in the field of MND research. Their passion and dedication was inspiring, and the thought that the person who will find a cure for MND could have been sitting in that room gave me goosebumps! You can read more about the event on pages 20 and 21.

Of course we can only fund vital MND research because of our wonderfully dedicated supporters who never cease to amaze me with their ingenuity and willingness to get stuck in. A big well done and thank you to everyone who took part in our Facebook challenge to Run 60 Miles In August. Our next Facebook challenge is our 75 Mile Dog Walk in October – raise more than £50 and your dog can be the envy of every pet in the park by sporting an MND branded bandana! I can't wait to see the photos online.

Meanwhile, we're approaching the busiest time of the year for the team which organises our International Symposium on ALS/MND. This year, for the first time since 2019, we will be meeting in person, as well as online, with hundreds of the world's top researchers, travelling to Basel in Switzerland to share ideas, collaborate and network. People affected by MND are welcome to join – you can find more details on page 11.

Please do share this issue of *Thumb Print* with your family and friends and maybe drop it off with a neighbour once you've read it – every copy is a chance to raise awareness with someone who perhaps doesn't know much about MND.

Tanya Curry, *Chief Executive*



# NextGen Think Tank summit

## welcomes Royal guest

**The positive impact of technology on people living with MND was showcased at a special summit attended by the MND Association's Royal Patron, Her Royal Highness, The Princess Royal.**

The Association organised the event, at Rolls-Royce headquarters in Derby, to highlight the work of its NextGen Think Tank. NextGen is a collaborative project, launched in conjunction with Rolls-Royce four years ago. It brings together some of the world's biggest companies to create ground-breaking technology to improve the quality of life of people living with MND.



The Princess Royal meets Diana Marsden who is living with MND

The summit focused on the multiple award-winning e-book *I Will Always Be Me*, developed by Rolls-Royce, Intel, Dell Technologies and the MND Association. When read out loud, the short e-book can electronically bank the voice of someone living with MND, allowing them to use this synthesised voice if they experience speech difficulties in the future. Previous voice banking options could take days, weeks or even months to complete.

Attending the event was Diana Marsden, who is living with MND and was

involved in the creation of *I Will Always Be Me*. She said: "It was both an exciting and emotional experience: a Royal introduction and meeting up with my 'Dream Team' friends for the very first time.

"Since the release of the *I Will Always Be Me*, four of us have kept in touch and share information, experiences and MND support projects. I will never forget the brief, long-overdue meeting with Yvonne, Alan and Mike, and how it gave us all something to look forward to – a date in the diary. We are very proud to have participated in the project and to see the positive effect it is having on people living with MND."

To date, more than 1,000 people have banked their voice using *I Will Always Be Me*. People with MND who volunteered their time to help trial the technology ahead of its launch in 2022 met Her Royal Highness, along with members of NextGen.



Diana Marsden and Alan Towart

Nick Goldup, Director of Care Improvement at the MND Association said: "We are incredibly proud of the innovative technology solutions developed by NextGen to improve the lives of people living with MND.



"*I Will Always Be Me* is a brilliant example of the impact NextGen can have. By encouraging some of the biggest companies in the world to collaborate, together we have revolutionised the voice banking experience for our community. It was an honour to share this exciting work with Her Royal Highness The Princess Royal and thank the wonderful people living with MND who supported this project from the very start."

Stuart Moss, Head of IT Innovation at Rolls-Royce and co-founder of NextGen Think Tank, said: "We were all delighted to welcome Her Royal Highness The Princess Royal, to Rolls-Royce where this collaboration started. It's the icing on the cake after what has been an incredible and inspiring year for NextGen Think Tank. I can't wait to see what we achieve next."

Other projects created by NextGen include Google's *Project Relate* and *Quips* which both focus on improving communication for people with affected speech.



Left to right: Nick Goldup, Director of Care Improvement, MND Association, Justin Ebert, Executive Creative Director for VMLY&R, Stuart Moss, Head of IT Innovation at Rolls-Royce, Tanya Curry, CEO, MND Association and Niraj Zaveri, Executive Creative Director for VMLY&R



**I Will Always Be Me is a brilliant example of the impact NextGen Think Tank can have. By encouraging some of the biggest companies in the world to collaborate, together we have revolutionised the voice banking experience for our community.**

Nick Goldup, Director of Care Improvement at the MND Association

Guests gather at Rolls-Royce headquarters to celebrate the work of NextGen Think Tank

## Driving creative communication

**Organisations involved in NextGen Think Tank have developed an innovative artificial intelligence (AI) art platform for people with MND.**

The *Mind's Eye* app is available for Grid Pad users and is designed for people with limited mobility – allowing budding artists to create bespoke artwork with just a few clicks. As well as sharing creations with friends and family, the tool offers an alternative way of communicating and expressing thoughts and feelings.

Organisations Area 23, Smartbox, Deep AI, Amylyx and the MND Association were involved in the project, and members of the MND community had the chance to trial and test the app ahead of launch. Mike Small, pictured right, who is living with



MND, said: "I was never interested in art until I started using *Mind's Eye*. Of all the things I can make, I am most excited to make myself understood." *Mind's Eye* is

set to be launched in autumn.

You can find out more and get started on the *Mind's Eye* website: <https://minds-eye.app/home>

# Improving wheelchair services

## The Wheelchair Alliance plans to transform

**It's estimated that around 80% of people with MND will need a wheelchair. Having the right wheelchair at the right time provides mobility and independence, enabling people with MND to take part in everyday activities in comfort.**

Wheelchair services can help with that. Which is why it's so vital that gaps in service provision are closed, and people's ability to get the right chair doesn't depend on where they live or how much money they have.

The Wheelchair Alliance aims to transform the experience for wheelchair users in England through improved access, quality and effectiveness of services. Recent research published by The Wheelchair Alliance provided evidence of a postcode lottery around the provision of wheelchairs. This variation is leaving some people with MND experiencing long delays in getting an NHS-supplied assessment and wheelchair, leaving others in wheelchairs unsuitable for their needs, and yet others having to pay for their own wheelchairs, adding to the financial pressures on people with MND.

The MND Association has strong links with The Wheelchair Alliance, through people with MND volunteering their time to support it, and Association staff including Nick Goldup Director of Care Improvement, who is also Chair of the Alliance.

Jean Waters is living with MND. She was a founder member of the Alliance and is now a board member.

She said: "I was involved with the MND Association's campaign to improve wheelchair provision and the creation of its supporting services for wheelchairs when I was a trustee of the charity. Personal difficulties in accessing a wheelchair and seeing the problems of others led to me wanting to get involved at a national level, and bring about change.

"Thankfully the experience I had getting my latest wheelchair was very different to my first. Those changes have come about because the Alliance created a *Wheelchair Charter*, outlining what good provision looks like. This



Jean Waters, board member of The Wheelchair Alliance



James Wheeler, member of the Alliance's user engagement forum



**Personalised assessment for my latest chair from the NHS was a breath of fresh air, with a proactive therapist aiming to ensure the chair worked as well as it could for me.**

brought greater awareness and interest from commissioners and providers, influenced by the Alliance and the National Wheelchair Advisory Group at NHS England.

"Personalised assessment for my latest chair from the NHS was a breath of fresh air, with a proactive therapist aiming to ensure the chair worked as well as it could for me. My one bit of advice for others with MND is please don't leave getting a wheelchair until you desperately need it and have exhausted all your MND limited pot of energy. The right wheelchair will enable you to do more and regain some independence both indoors and out."

James Wheeler is living with MND and is a member of the Alliance's user engagement forum.

He said: "My initial experience of obtaining, first my manual wheelchair and now my power chair was



**As somebody with MND, I think it's also especially important that we, as a particular user group, are represented at this level given the complexities of our needs.**

horrendous. The lead time was very long and there were many complications along the way. I found out that this was a similar experience for many people, so I set about campaigning through my local MP. Fortunately, AJM, my service provider, listened to the feedback and put steps in place to try and improve the service user experience. They invited me to be a part of their user forums and I've been helping them for the last three years. They have made many positive changes to how they operate and the service we receive here in Derbyshire is much better.

"The Alliance can influence the experience of wheelchair users, their families and their carers at a very high level in the UK. As somebody with MND, I think it's also especially important that we, as a particular user group, are represented at this level given the complexities of our needs.

"My one piece of advice for people

# the experience

with MND is to make sure that you and your occupational therapist are communicating effectively with your local wheelchair service. Getting the right wheelchair prescription early and reviewing it often will help keep you safe and comfortable in your chair. Your service provider is responsible for keeping the chair repaired and in good condition, but if this isn't the case do talk to them."

The Wheelchair Alliance is a lobbying group and the voice of wheelchair users at national level. However it's unable to advocate on individual cases – this should be done through the local commissioner. If you would like to help improve wheelchair provision for people with MND, please ask your local wheelchair service to set up a wheelchair user group that includes a person living with MND.

For more information on the work of the Alliance visit [www.wheelchair-alliance.co.uk](http://www.wheelchair-alliance.co.uk) If you have any questions or experience any problems with access to a wheelchair, please email [wheelchairs@mndassociation.org](mailto:wheelchairs@mndassociation.org) or contact MND Connect on 0808 802 6262.

## Wheelchair Support Service

**In the last 12 months, the MND Association's Wheelchair Support Service has provided more than £111,000 in support grants, enabling 125 people with MND to access wheelchair accessories such as powerpacks, risers, attendant controls and powered elevated leg rests.**

Richard Long is living with MND and received funding from the MND Association for additional features to his new wheelchair. He said: "My new chair is all singing and dancing. The back reclines, the legs raise up, the entire seat tilts back, moving the pressure from your backside to your back. The seat also rises, allowing eye-to-eye

conversations without people having to look down at me and me having to constantly look up. It's extremely comfortable and I can use it indoors. The cost was not fully covered by the NHS and the MND Association funded the difference, including providing grants for the additional features, with me making a small contribution."

As well as financial grants, our Wheelchair Support Service also provides advice and support to people with MND and healthcare professionals through two specialist therapists funded with support from the Alan Davidson Foundation, Lynne Hills and Maggy Hevion. Lynne and Maggy's tips include:

- **Seek an early referral from your GP to your local wheelchair service provider**
- **Ensure your current and future needs are taken into account**
- **Seek specialist support through the Wheelchair Support Service Team at the MND Association to help you make an informed choice.**

The Wolfson\*  
Foundation

### The Wolfson Foundation

Special thanks to The Wolfson Foundation which has donated £75,000 to the MND Association to fund wheelchair accessories and communication aids for people living with MND to improve their quality of life. The Foundation has supported the Association for more than 30 years, awarding £1.5m.

Alan  
Davidson  
Foundation

### The Alan Davidson Foundation

The Alan Davidson Foundation has generously supported the MND Association since 2015 and, alongside other support, is providing annual funding for our wheelchair service.



Richard Long who has received funding from the Association for wheelchair accessories



## YOUR STORIES

# Our day on the cobbles

**Sam Hayden-Harler, who is living with MND, and his husband James spent a day on the country's most famous cobbled street. They met actor Peter Ash, whose character Paul has MND, and Association ambassador Dan Brocklebank who plays Paul's on-screen partner. Here Sam shares his story of the day.**

**We were warmly welcomed to the set of *Coronation Street* at ITV studios, where we were blown away by the intricate detail and the realistic external features, and how everything looked lifelike. However, not all is as the eye sees and there are some very clever tricks in how the set is built.**

James and I were surprised to discover that when you go inside the homes, you can walk along the row of houses internally, as they're not individual houses! We spent ages walking around, having pictures taken, and hearing about new parts of the set recently built for upcoming storylines.

We went into the studio where the scenes for the *Rovers Return* are filmed. We caught the end of the scene, shortly before meeting Claire Sweeney, and stopping to have a chat with her, before a well-needed lunch break.

After lunch, we returned to the cobbles to meet with Peter and his on-screen husband, Billy, played by Daniel Brocklebank. They were both very

welcoming and interested to hear of my own story. We spent time chatting about why the storyline featured in *Coronation Street* is needed more than ever, to bring real conversations into the limelight about those living with MND and the impact this has on those around them.

Daniel talked about the loss of his grandfather to MND and how some things are extremely upsetting for him to film, but he knows how important this storyline is to the MND community. I also spoke with Peter about how his character's diagnosis was almost identical to mine. I asked him about the physicality of portraying somebody with MND, and if he finds it difficult. He explained how he was aware he would need to change and adapt as the storyline progresses.

We then took a front row seat just behind the camera as Peter and Dan's scene was being filmed. We watched Paul and Billy facing difficulties in accessing their home due to the size of the electric wheelchair and how it would not fit through the door. Watching Peter play

a character was important for me to see and how his own physical appearance is like my own in that I struggle to use my hands and legs.



**Daniel talked about the loss of his grandfather to MND and how some things are extremely upsetting for him to film, but he knows how important this storyline is to the MND community.**

We were comforted to know that *Coronation Street* is in constant contact with the MND Association to ensure that the storyline and what is seen, is a realistic portrayal of those living with the disease and those who support them. We had a great time visiting *Coronation Street*, and we know how important it is to them to get the storyline just right.



# Benefits Advice Service

helps identify benefits entitlement

**David Mangan is one of hundreds of people living with or affected by MND who has contacted the Association's Benefits Advice Service in the past year. David wanted to find out what benefits he was entitled to, so called the service to speak to a qualified adviser.**

This support has been a huge help to David, pictured right, as he explains: "The MND Association Benefits Advice Service has been fantastic. They give great advice, and they will follow up a few weeks after a call, ask where we've got to with applying for things, and encourage us to carry on with applying if we haven't."

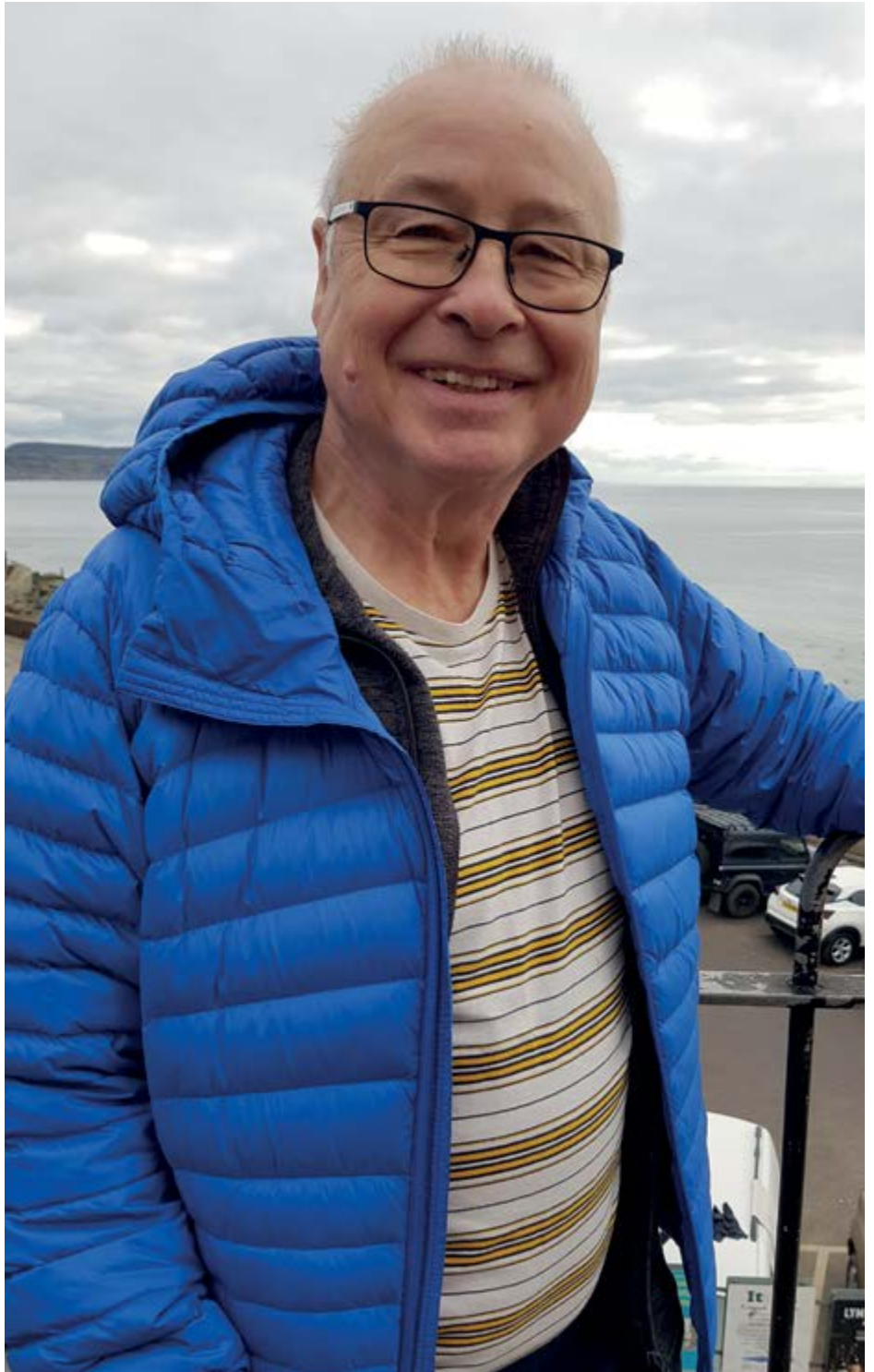


**The MND Association Benefits Advice Service has been fantastic. They give great advice, and they will follow up a few weeks after a call, ask where we've got to with applying for things, and encourage us to carry on with applying if we haven't.**

As well as identifying benefits, advisers can also deal with complex benefits issues and appeal against decisions, like they did for Lucy, who is living with MND. Lucy had a standard rate PIP Daily Living award, but due to her multiple health conditions she wanted to apply for the enhanced rate. Lucy had found the benefits process challenging and believed the health interviewer had underestimated her mental health difficulties. She was initially refused the enhanced rate.

Our advisers started the appeals process. Alongside this, Lucy was signposted to other sources of support such as charitable grants, help with home adaptations and driving support. Advisers completed the necessary forms and drafted letters for Lucy to send to her health professionals requesting evidence of her conditions.

The appeal was successful and Lucy was offered the enhanced rate of PIP to include a daily living allowance, receiving



*David Mangan, who is living with MND*

a backdated payment of £6,846 and then ongoing payments of £172 per week. Lucy said: "Thank you for the incredible work you've done on this. On top of managing MND, the whole PIP situation has added an incredibly negative level of stress and uncertainty to my personal situation. Thank you once again."

**To find out more about this service and how to speak to an adviser please visit [www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice) complete an online form, start a web chat or call an adviser.**

# Triathlon Impossible...

## made possible



**As a former Rugby League coach, watching what has happened to Rob Burrow and meeting so many people across the country who've been impacted by MND, this attempt was for them, fighting the disease every day.**

**Former Rugby League coach, Martyn Clarke is no stranger to marathons and triathlons, but Martyn's Triathlon Impossible, raising money for four MND charities, was the test of his life.**

The epic challenge, a test of physical and mental endurance started on 24 June when Martyn dived into the 7km swim leg in Frankfurt, Germany. He then cycled more than 750 miles through Germany, the Netherlands, Belgium and France before arriving in England, where he completed his final stint – a 58-mile run, from Headingley Stadium in Leeds, home of the Leeds Rhinos.

Six days, seven hours and 41 minutes after that first dive into the cold Frankfurt lake, Martyn was cheered across the finish line at Leigh Sports Village in Greater Manchester, just in time to catch the live Super League Game between Leigh Leopards and Hull KR.

Throughout the challenge Martyn was joined by special guests and supporters, which included Team GB Paralympian Ian Marsden. BBC Triathlon reporter Annie Emmerson and Leigh Leopards owner Derek Beaumont were among the ambassadors for the event. A support team including former England Lioness, Izzy Christiansen and Mayor of Manchester, Andy Burnham kept Martyn's spirits up.

Cycling for up to nine hours a day, in temperatures of 40 degrees, up elevations as

high as Everest, with three hours sleep, before the ultra-run from Leeds to Leigh over the Moors took a significant toll.

Martyn said: "This was the most demanding endurance event I've attempted for four MND charities. By the end my legs were destroyed, but I was grateful for the amazing support of the team, and was driven by everyone suffering with MND.

"As a former Rugby League coach, watching what has happened to Rob Burrow and meeting so many people across the country who've been impacted by MND, this attempt was for them, fighting the disease every day.

"For seven days we fought the pain, heat, fatigue, but we got the chance to recover, some aren't so fortunate. At the age of 49, to attempt this brought its own risks and safety concerns, completing the treble of endurance attempts was pushing the boundaries. We were supported closely by Sports Science MSC students at Leeds Beckett University."

Triathlon Impossible has raised over £19,240 for the MND Association, My Name's Doddie Foundation, the Darby Rimmer Foundation and the Rob Burrow Centre for Motor Neurone Disease appeal run by Leeds Hospitals Charity.

**If you would like to make a donation to Martyn's fundraising page visit <https://donate.giveasyoulive.com/fundraising/triathlonimpossible2023>**



*Martyn pictured left with members of his team*

# International Symposium on ALS/MND



**After three years in a virtual environment, we will be bringing the international research community back together for the in-person 34th International Symposium on ALS/MND. The event, hosted this year in Basel, Switzerland from 6 to 9 December, plays a fundamental role in facilitating the exchange of exciting new knowledge, as well as stimulating new ideas and partnerships.**

While we are looking forward to meeting back in person, we know holding the Symposium online enabled those unable to travel to participate in the event. To continue making the event accessible to a wider audience we will be live streaming a select number of sessions. 'Online' delegates will have access to live streaming and on-demand access to all sessions after the event.

Every year, the Symposium showcases the breadth of MND research across the globe. The programme includes plenary presentations from 14 international leaders in MND research.

Dr Angela Genge, from the Montreal Neurological Institute and Hospital, will explore the use of signals of MND within the body (also known as biomarkers) in clinical trials. This is a hot topic in MND research, given the pivotal role played by one biomarker in the approval of the treatment, Tofersen (Qalsody), in the USA earlier this year. Dr Genge will discuss how these markers could potentially be used to help select 'the right patient for the right trial' and pave the way for more personalised treatment options.

Our programme also includes a talk from Professor Eneida Mioshi from the University of East Anglia. Professor Mioshi's research aims to address the impact cognitive and behavioural changes have on daily life and the care of people with MND. She will discuss the development of the online MiNDToolkit. The toolkit aims to help carers better manage behavioural and thinking symptoms and hopefully improve the quality of life of

those living with MND.

From the Tokyo Metropolitan Institute of Medical Science, Professor Masato Hasegawa will discuss his research into a faulty protein called TDP-43. In around 97% of all MND cases, TDP-43 is found in the wrong place in neurones. Professor Hasegawa will present recent results which look more closely into the role TDP-43 plays in MND and how understanding this role could help lead to potential new therapies.

**Registration for the Symposium is open. Both in person and online places are available. Please visit: <https://symposium.mndassociation.org> to find out more.**



*This year's Symposium will be taking place in the beautiful city of Basel, Switzerland*

# Through the roof – the effect of high energy prices



**Like many people who are living with MND, Mark requires equipment powered by electricity to keep him comfortable. With high energy prices, Mark and his wife Nicola are increasingly struggling to keep on top of the bills.**

Nicola said: “We’re using a lot of electricity because Mark requires so many pieces of assistive equipment to keep him alive and independent – two hoists, wheelchair, ventilators, back-up ventilators, humidifier, the list goes on. They all run on electricity, and they all cost money to run.

“If Mark was in hospital, this would all be paid for but I’m having to absorb all the costs of the disease. I’m running a small hospital from home and I’m paying dearly for it. My monthly electricity bill was £800. How is this affordable? I’m doing my absolute best by Mark, but it’s unsustainable.”

It’s not just the cost of electricity that people with MND are having to cover. There are other significant costs linked to managing MND, as Nicola explains: “Mark requires 24 hour care and we’re supported by a team of 13 nurses and carers. This all comes with extra household costs. You’re washing out syringes all day, you need to prevent infection and that requires such a high level of cleaning and therefore water usage. You need to keep the heating on for the carers. These are the costs of MND



*Kin Tung Wong (KT) who is living with MND, and his wife Kuai Peng. Like many, they rely on a range of electronic assistive equipment to keep KT alive and as independent as possible*

people don’t really think about.

“When given such a devastating diagnosis all you want to do is focus on your loved one and make them feel as safe, supported, loved and comfortable as

possible. You don’t want to be worrying about paying bills and funding. The Government have it in their power to make this life-changing situation more bearable.”



**£14,500+**

Households affected by MND spend an average of £14,500 a year on the costs of living with and managing the condition, with many households spending much more.



**28%**

72% of MND households rely on assistive equipment, but 28% have reduced the use of this equipment in the last 12 months in response to rising energy costs.



**51%**

People affected by MND are cutting back on food and turning down the heating. Over half (51%) have reported their household experienced difficulties paying for food, home, heating and energy over the last 12 months.



**52%**

Over half (52%) of people affected by MND are worried about being able to pay their mortgage over the next 12 months.



PROMISE 4  
WE WON'T REST UNTIL  
YOU ARE HEARD

# THROUGH THE ROOF

In September, the MND Association launched its report – *Through the roof: The experience of households affected by MND during the cost of living crisis* – calling on the Government to safeguard families affected by MND against the financial impact of the cost of living crisis.

The report is based on the experiences of 83 families, collected through a survey by the Association at the beginning of the year. It found that people affected by MND have been disproportionately affected by the crisis. In many cases, rising costs have forced people to make difficult, and sometimes impossible, choices between essential living expenses and their own health and wellbeing.

People told us they were facing three key issues: affording basic living essentials, difficulties managing a reduced income, and prioritising their health and wellbeing. We found that the average yearly cost of living with and managing MND is £14,500, but some families can spend much more. The crisis has exacerbated this financial impact for households. Many people lose their incomes because of their condition, and carers often must reduce their working hours or stop working altogether to provide care.



**Heating is on most of the time as my husband's muscles become extremely painful if he gets cold.**

Survey respondent

While everyone has experienced rising costs, people with MND have been disproportionately affected. On average, it costs people up to £600 a year to use and charge assistive equipment which keeps them safe and helps retain independence. Families managing advanced stages of

the condition can spend between £800 and £900 a month on electricity alone – equating to an astronomical £10,000 a year – on top of other household bills. These costs are catastrophic but inescapable.

Most alarmingly, we found that more than a quarter (28%) of people have been limiting their use of assistive equipment in the previous 12 months in response to rising energy costs. This places their health and wellbeing at significant risk.

More needs to be done to ensure that people are not plunged into financial hardship because of their condition. Government had promised to consult on proposals on more targeted energy support – such as an energy social tariff – in 2022 and 2023. But this has not happened, and the energy crisis is not over. We are therefore asking Government not to renege on their promise to consult on targeted energy support.



**The cost of living crisis has impacted us terribly. Not only have the bills gone through the roof but we are being evicted under a no-fault Section 21.**

Survey respondent

To raise awareness of this issue, the Campaigns, Policy and Public Affairs team will be hosting a meeting in Parliament for MPs and Peers to hear about the report's findings. They will be asked to sign a joint letter to Government asking them to commit to taking action on the issues it raises, to protect people living with MND against spiralling costs.

**If you are living with MND and are struggling with household bills or food shopping you can apply for a one-off grant of up to £350 online at [www.mndassociation.org/costofliving](http://www.mndassociation.org/costofliving) or by contacting MND Connect on 0808 802 6262. We can also offer guidance about benefits through our Benefits Advice Service (page 9).**

## In the past year:

# 74%

Reduced their heating

# 51%

Said they had difficulties paying for food, home heating and energy

# 68%

Plan to cut down on energy use

# 63%

Plan to use savings to pay for essentials

# 27%

Plan to cut down essentials such as food

# Meet Hazel Carter

## our newest Board member

**“My husband had an aggressive form of ALS and lived for 18 months with me as his primary carer, until he died in 2019. We had amazing support from the MND Association, our local branch and the hospital and hospice, which helped us with every aspect of care, both physical and psychological.**

“My 43 year career was in business to business sales, marketing and business development. I worked at board level for the last ten of those years. My whole working life has been focused on the customer experience.

“For several years I’ve fundraised for the MND Association, volunteered as a campaigner for my local branch and regularly attended MND support meetings. My goal is to help the MND Association maintain absolute focus on people living with MND and their family and friends. I’m passionate in wanting better support, in particular psychological support for those affected by MND. I want to see best practice care across the whole of the UK, while work is going on to find treatments and a cure.”

We thank all our members who considered and put themselves forward as a trustee. We will be looking to develop further ways that our members can get involved in our governance.



**My goal is to help the MND Association maintain absolute focus on people living with MND and their family and friends. I’m passionate in wanting better support, in particular psychological support for those affected by MND.**

You can find out more about our trustees on [www.mndassociation.org.uk/trustee](http://www.mndassociation.org.uk/trustee)



**Reflecting on a busy period for the Association over the summer, we now find ourselves moving into an autumn of hope and expectation.**

For the Board, we said our farewells to Siobhán Rooney and Katy Styles, two trustees who added huge value to the Board and the Association during their periods in office, and who will be missed. Our elections were the most successful ever with regard to candidates putting their names forward. I’m very pleased to congratulate Hazel Carter for her success in gaining the most votes and joining us on the Board.

For the Board, our focus continues to be on ensuring we work towards our vision of a world free from MND. We do this by supporting cutting edge global research, ensuring support is available to all those living with MND during these times of particular financial challenge, and making sure politicians and policymakers give MND the focus it so rightly needs and deserves. As a Board we are also focused on staying close to the MND community and I, and others, will be out and about at Branch events to ensure that your views, thoughts and needs stay central to everything we do.

# Speeding up the search for effective treatments



**By using these innovative approaches to drug trials, more people living with MND will have the opportunity to get involved in trials and this in turn will help drive forward the hunt for effective treatments.**

Dr Brian Dickie MBE, Director of Research Development

**The MND Association is funding two key research programmes which aim to speed up the search for effective treatments of MND. £500,000 has been committed to MND-SMART, the UK's largest MND clinical drug trial. The innovative trial tests medicines that are already approved as treatments for other diseases in the UK (repurposed drugs).**

The design of MND-SMART allows for multiple drug treatments to be tested at the same time, speeding up progress and reducing the number of people with MND assigned to the placebo (dummy drug) group. Three potential drugs are currently being tested, with more than 500 participants recruited.

Our investment will help maintain the infrastructure to allow MND-SMART to test new drugs for years to come, giving more people with MND a chance to take part in a clinical trial.

The MND Association has also pledged its support to a new experimental medicine platform designed to rapidly test promising treatments. EXPERIMENTAL

Route to Success in ALS (EXPERTS-ALS) aims to quickly identify the most promising drugs to take forward to be tested in larger phase 3 clinical trials, such as MND-SMART.

Phase 3 trials are expensive, time-consuming and their success rate has been very low. This is partly because the drugs put forward for testing have often been chosen largely on data from laboratory studies, rather than from people living with MND. EXPERTS-ALS enables selected drugs to be tested in people with MND earlier rather than continuing testing in the lab, to investigate if they show early signs of benefit.

The platform will initially test repurposed drugs in small groups of people with MND for up to six months. Blood tests will be used to look for early signs of benefit allowing the most promising drugs to be prioritised for testing in larger phase 3 trials.

EXPERTS-ALS is currently being setup and researchers hope to begin testing drugs in the summer of 2024. This flagship

project of the newly-created UK MND Research Institute is being funded by the Department of Health and Social Care (through the National Institute for Health and Care Research), with additional investment from the MND Association, MND Scotland, My Name's 5 Daddie Foundation and LifeArc.

Dr Brian Dickie MBE, Director of Research Development at the MND Association said: "We are delighted to continue to support the MND clinical trial infrastructure in the UK, aiding the clinical testing of potential new therapies. None of this would be possible without the support from those who have generously donated to the MND Association. By using these innovative approaches to drug trials, more people living with MND will have the opportunity to get involved in trials and this in turn will help drive forward the hunt for effective treatments."

**If you are interested in taking part in MND research, you can find out more on our website [www.mndassociation.org/treatment-trials](http://www.mndassociation.org/treatment-trials)**

# Rugby League community shows support for MND

**A West Yorkshire derby between Leeds Rhinos and Huddersfield Giants on Friday 23 June was so much more than a dedicated MND awareness game. The day was a celebration of how the Rugby League family has supported the MND community, since Rob Burrow's diagnosis of MND in December 2019.**

MND Association patron Rob Burrow MBE and his family were guests of honour at the match, with the rugby legend's children playing a big part in the special day. His daughters Macy and Maya, were part of a dance performance along with 777 children – in recognition of Rob's playing number 7 – before the game, while Rob's son Jackson delivered a specially produced match ball before kick-off.

The fixture, aired on Sky Sports, came just 48 hours after Global MND Awareness Day on 21 June. The Leeds Rhinos wore their Doddie Weir tribute kit in a show of support for MND charities and the late Doddie Weir, who died of MND in 2022. Local BBC and ITV news programmes interviewed members of the MND community, including Huddersfield Giants fan Adam Keating, who ended his eight-day sponsored walk at the match, raising £400 for the Association.

Leeds Rhinos and Huddersfield Giants donated 20% of the money from the sale of match tickets to the MND Association. The tickets, along with a bucket collection by local MND Association volunteers, raised £10,000.

Sue Lodge, who is living with MND, accepted a giant cheque on behalf of the MND Association from Rugby League Commercial for £25,000 from the sales of special MND England Rugby League shirts from the England v France friendly in April.

Leeds Rhinos Commercial Director Rob Oates said: "Every time Rob and his family come to a game it's always a special occasion, but we particularly look forward to our annual MND awareness game. As a sport, Rugby League has embraced the MND community since Rob's diagnosis and the local derby was a great opportunity for us to celebrate that together."



**As a sport, Rugby League has embraced the MND community since Rob's diagnosis and the local derby was a great opportunity for us to celebrate that together.**

Rob Oates,  
Leeds Rhinos  
Commercial Director



Members of Rob Burrow's family together with representatives from the MND Association, Leeds Rhinos and Huddersfield Giants took part in the derby celebrations



# Gastrostomy tube – is it for me?

**The DiAMoND web-based patient decision aid has been developed to help people with MND consider if a gastrostomy tube for tube feeding is right for them.**

Using joint funding from the MND Association and Marie Curie, researchers at Southampton University have created the online tool, *Gastrostomy tube – is it for me?* at: [gastrostomychoice.co.uk](http://gastrostomychoice.co.uk)

MND can cause difficulties swallowing, which can lead to coughing, longer mealtimes and food 'going down the wrong way' (aspiration). These effects can lead to repeated chest infections, poor nutrition and weight loss. A gastrostomy feeding tube can help avoid or reduce these issues. Gastrostomy refers to the opening through which the feeding tube enters the stomach.

Dr Sally Wheelwright led the project to develop the DiAMoND patient decision aid which also involved people living with MND and their carers, clinical experts and healthcare professionals.

If you're living with MND, the new tool uses questions to help you decide whether to have a tube fitted now

or think about this later. In giving the risks and benefits for each choice, the evidence-based content can also support discussions and shared decision making with your health and social care professionals.

Our information sheets 7A – *Swallowing difficulties* and 7B – *Tube feeding* also provide guidance. Find these publications along with our *Eating and drinking guide* at: [www.mndassociation.org/eating](http://www.mndassociation.org/eating)

This web page also features another decision aid for tube feeding, called myTube, developed by the Sheffield Institute for Translational Neuroscience (SITraN) and part-funded by the MND Association. Using videos of people living with MND and their carers, myTube introduces what it's like to live with a feeding tube: [mytube.mymnd.org.uk](http://mytube.mymnd.org.uk)

**If you would like to know more about our publications or order printed copies, contact our MND Connect helpline: 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**



Dr Sally Wheelwright, Senior Research Fellow at Southampton University

## "I like anything fruity, especially a martini"



**Dad-of-two Steve Wharton, pictured left, has found a way to experience his favourite tastes again after being unable to eat and drink for over a year after being diagnosed with MND.**

Steve, aged 36, was diagnosed in 2020 and lives with a PEG, tracheostomy, ventilator, cough assist and suction machine. He applied for an MND Association Quality of Life grant for funding towards a Biozoon Air kit.

Biozoon is a dissolvable foam, through which people who are unable to swallow, can continue to experience their favourite tastes. Steve, who is a big fan of a martini, said: "MND has changed every aspect of my life. I miss playing with my kids and eating the most. The Association has supported me and my family in a big way.



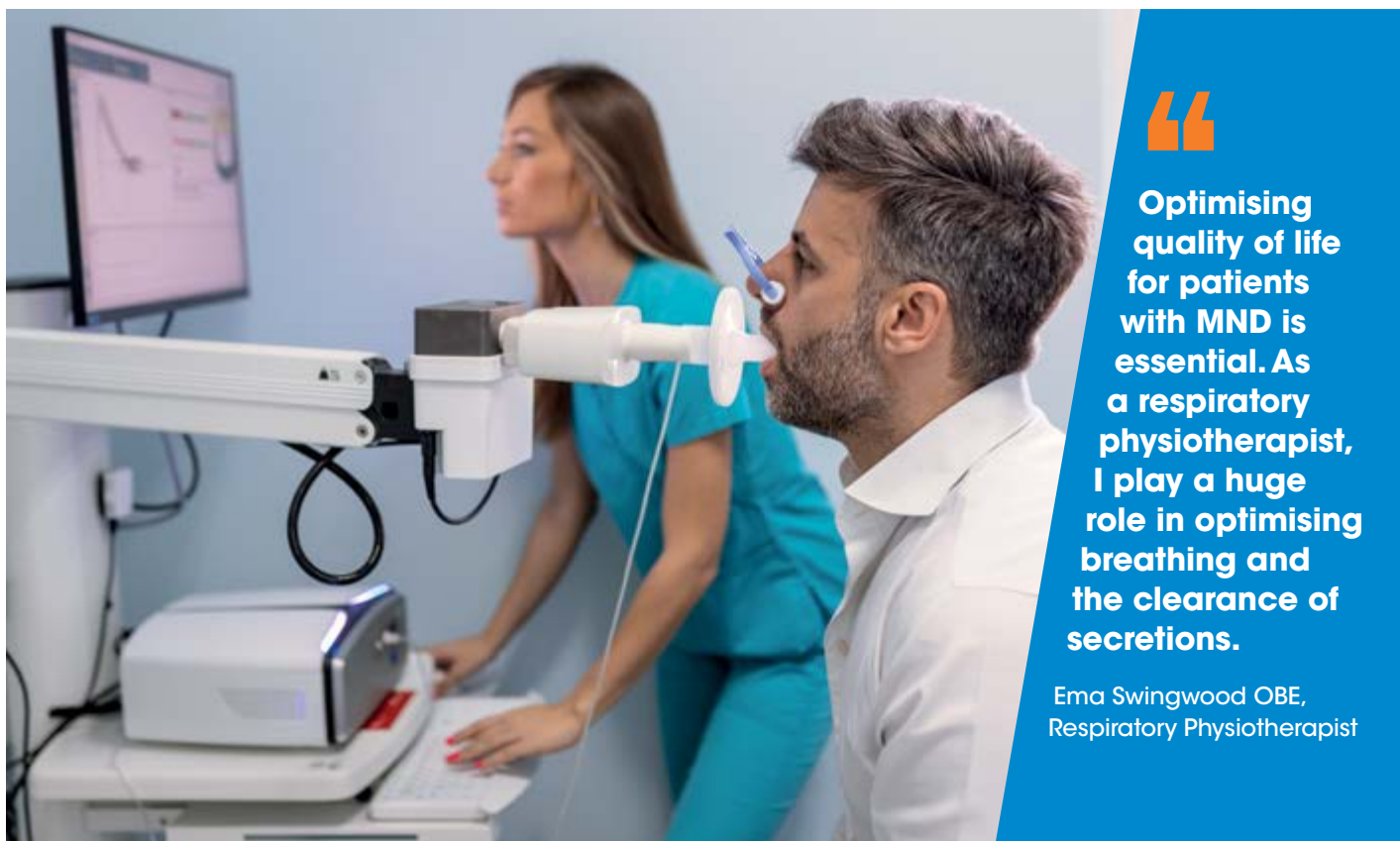
**We were able to get much needed items. It was my speech and language therapist who applied on my behalf for Biozoon so I could continue experiencing tastes. I've been unable to have food and drink for over a year.**

We were able to get much needed items. It was my speech and language therapist who applied on my behalf for Biozoon so I could continue experiencing tastes. I've been unable to have food and drink for over a year. It feels amazing to give my taste buds a workout again. Biozoon makes a big difference; tastes can lift your morale. I like anything fruity, especially a martini."

# Meet the professionals: Respiratory management



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



**Optimising quality of life for patients with MND is essential. As a respiratory physiotherapist, I play a huge role in optimising breathing and the clearance of secretions.**

Ema Swingwood OBE,  
Respiratory Physiotherapist

**People with MND can be in touch with up to 20 different health and social care professionals. Our regular 'Meet the professionals' feature, spotlights the different professionals and how they support people living with MND.**

In most people with MND, the muscles used for breathing (called the respiratory muscles) are affected as the disease progresses. This can cause fatigue, breathlessness and anxiety, and can have a significant impact on a person's quality of life. Treatments and support for breathing issues are commonly referred to as respiratory care or respiratory management. For people with MND, early breathing assessment is crucial, and some services can offer this from the time of diagnosis.

## **The respiratory team**

The respiratory team responsible for the assessment may include respiratory physicians, physiologists, physiotherapists, and specialist nurses. They will assess breathing and coughing abilities, and recommend suitable therapies and treatments to help relieve symptoms. This may include breathing exercises, assisted ventilation, and techniques to aid with coughing and clearing secretions. Regular monitoring of breathing every two to

three months will ensure the treatment plan is adjusted as symptoms change.

The respiratory team works closely with other professionals to ensure breathing problems are managed. Ema Swingwood OBE, is a Respiratory Physiotherapist at University Hospitals Bristol and Weston NHS Foundation Trust. She explains why it's so important to work as part of a team.

She said: "Optimising quality of life for patients with MND is essential. As a respiratory physiotherapist, I play a huge role in optimising breathing and the clearance of secretions. However, I would not be able to do this without the work of the multidisciplinary team and I work with some amazing doctors, nurses and physiologists. We work together with the patient and their loved ones, enabling them to live the best life that they can."

It's not just the respiratory team that can provide support in managing breathing difficulties. For instance, a district nurse can provide an adjustable bed, an occupational therapist can offer an adjustable chair and postural support,

and a speech and language therapist can assist with controlling breathing while eating. The GP, palliative care team, or neurologist can address symptom management, including anxiety and saliva-related concerns.

## **Accessing support**

The NICE guideline on MND includes specific recommendations about respiratory function and symptoms, cough management and ventilation. It recommends that a respiratory physiologist or a healthcare professional who can assess respiratory function should be a core part of the MND care team. If this is not the case for you, ask any member of your care team to refer you.

The MND Association has a range of information sheets on breathing problems and ventilation for MND.

You can download these from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies by calling 0808 802 6262 or emailing [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

# Proven medicines – working for access

**MND research is in an unprecedented time. After decades of research, there are now potential medicines moving further along the pipeline, with the possibility one or more could become proven treatments.**

As and when that happens, as the leading charity working for people with MND, the Association wants all people with the disease to be able to explore the options available to them, and have informed conversations with their neurologists.

Since April this year, the Association has been working with people with MND, organisations and individuals with expertise in this area to understand the processes and systems involved in that. This includes regulatory processes and also early access programmes. Both of these can be lengthy, complicated and involve multiple agencies. Often that is for good reason – it’s important to ensure medicines available for prescribing by clinicians are safe, effective and available to all they would benefit.

A key part of the work has been to understand where the Association can and can’t make a difference to ensure we are focusing our efforts in the right area.

Chief Executive Tanya Curry explains: “With some of the world’s leading researchers talking positively about medicines which may slow the progress of MND, this is a real moment for all of us in the MND community and it’s important we use our resources in the right way.

“We have learnt so much working with a number of people and organisations over the last few months and it’s now much clearer where we can influence and affect processes and decisions, and importantly where we can’t. We must concentrate our efforts where we can make a difference.

“One of our strengths is our role within the MND community and we’re already using that to ensure your voices are heard by decision-makers.”

Earlier this year, the Association provided information and attended a workshop as part of the scoping consultation being carried out by the National Institute for Health and Care Excellence (NICE) around access to Tofersen by people with MND carrying the SOD1 gene mutation. We continue to be involved in NICE discussions about Tofersen.

And in June we accepted an invitation



**With some of the world’s leading researchers talking positively about medicines which may slow the progress of MND, this is a real moment for all of us in the MND community and it’s important we use our resources in the right way.**

from NICE to support a scientific advice project specific to MND – we attended a meeting along with a person living with MND.

More recently, we have gathered information from a group of people living with MND to add to an application to NHS England’s Drug Repurposing Scheme to look at the repurposing of Proleukin.

**Regular updates around this work are being published on the latest news section of our website:**  
[www.mndassociation.org/media/latest-news](http://www.mndassociation.org/media/latest-news)

## MND trials in the pipeline

Medicine	Trial status	Next steps	Upcoming milestone
Interleukin-2	MIROCALS Phase 2 completed	Awaiting trial results	Trial results due in the coming months
Tofersen	ATLAS Phase 3 completed 2021	Company now seeking approval in Europe and UK via regulatory bodies eg NICE	Approval and licensing
AMX0035 (combination therapy of TUDCA and sodium phenylbutyrate)	PHOENIX Phase 2 completed 2021	Phase 3 trial ongoing Expecting trial results 2024	Company use of Phase 2 data to obtain early approval, turned down by European Medicines Agency (EMA). Company appealed with results of that appeal expected October 2023. Company has approached NICE.
Tauroursodeoxycholic acid (TUDCA)	TUDCA-ALS Phase 2 completed	Phase 3 trial results	Results expected by end of 2023
Oral Edaravone	ADORE Phase 3 trial underway	Results expected 2024	Submission to regulatory bodies if data positive. The company has approached NICE regarding approval already.

# Securing the next generation of MND researchers

**Some of today's leading MND researchers received support from the MND Association at the start of their careers, giving them the opportunity to develop their scientific expertise and placing them at the heart of MND research.**

By supporting the work of early career researchers we're helping to secure the next generation of MND research leaders. That's why last year we launched a two-day event for young scientists, to inspire them to collaborate, connect and focus their careers on ending MND.

Our MND EnCouRage event returned in July with more than 20 early career

researchers attending alongside people living with and affected by MND, established and leading researchers, and expert speakers. Guest speaker, television and science presenter Dallas Campbell, kicked off the event with *How to give brilliant talks*, helping the researchers understand how to present their science in the best way to a lay, or non-scientific, audience. The researchers then put Dallas' tips into practice by showcasing their projects from the stage during three minute 'lightning talks'.

For most of the researchers, this event was their first opportunity to meet and hear from people living with MND. Sarah



Early career researchers attending the EnCouRage event in July



Left to right: Mandy Spencer, Harriet Marriott, Andrew Waller, Margaret Waller



Dallas Campbell, television and science presenter

Granger, MND Association-funded PhD student at the University of Sheffield, said: "This is the first conference I've attended where there are people who are living with MND or have been affected by the disease. It's been really eye opening for me and also reinforced why we have such a collected effort to find therapies for this disease."

Speaking at the event, Ammar Al-Chalabi, Professor of Neurology and Complex Disease Genetics from King's College London, said: "These events are



**The interactions with people living with MND, it's always a privilege to be able to really reinforce why we do the work we do and get grounded in the bigger picture.**

*Allan Shaw, PhD student at University of Sheffield*



**It was great to be involved in MND EnCouRage, not only to meet all the wonderful early career researchers involved in MND research but also to meet people affected by MND. It was truly inspirational to see the great breadth of translational and clinical work!**

*Heather Marriott, PhD student at King's College London*



**It's been an incredible event. What really stands out is the commitment of all the individuals, from different backgrounds and experiences, working together as a team.**

*Stephen Mallett, living with MND*



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



**“**  
**By investing in these incredible researchers we are investing in a cure for MND – one of the people in that room could find the cure we all desperately want.**

Mandy Spencer,  
 Research Engagement Officer

advice and knowledge, we hope to increase collaboration, give them more understanding about what their work means to the MND community and encourage them to remain working in the field.”

Planning has already started for next year's EnCouRage event. To find out more visit <https://mndresearch.blog/2023/07/12/mnd-encourage-uk-one-of-the-early-career-researchers-may-hold-the-cure-in-their-hands-they-just-dont-know-it-yet>



Sarah Granger, Association-funded PhD student at University of Sheffield

very important to early career researchers. It gives them an opportunity to network and collaborate with other researchers. You learn skills you won't learn anywhere else. For example, we learned what it's like to live with MND because people with MND are at these events. If you are a basic scientist you may not otherwise interact with people living with the condition – it's very important to do so.”

During the two days, the researchers also had question and answer sessions, heard talks about how to involve people

with MND in drug discovery and practical help with understanding research papers and the wider research landscape.

MND Association Research Engagement Officer, Mandy Spencer said: “By investing in these incredible researchers we are investing in a cure for MND – one of the people in that room could find the key we all desperately want.

“By bringing them together, introducing them to established leaders and giving them new tools,



**It's been amazing! I think the best part has been getting to meet a lot of other early career researchers who are doing the same type of work we're all trying to work towards – which is helping MND.**

*Dezeræe Cox, MND Association Research Fellow, University of Cambridge/UK Dementia Research Institute*



**Had a great two days at MND EnCouRage meeting lots of early career researchers and hearing about amazing research. It's been a privilege as well to be able to present my work to people living with MND.**

*Marianne King, postdoctoral researcher at University of Sheffield*



**It's exceeded my expectations: really worthwhile in terms of actually understanding what amazing work is going on and also the range of the work and how people collaborate, which is what science is all about**

*Daniel Ackerley, living with MND*

# A stepping stone to a research career in MND

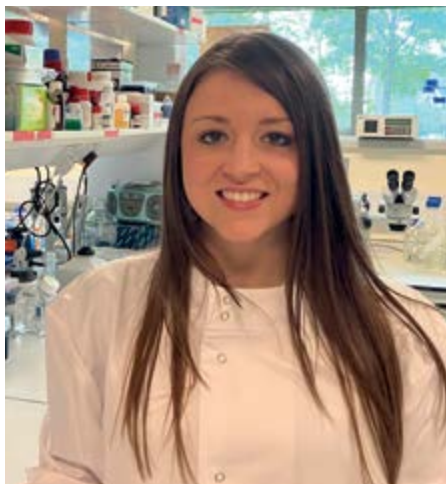
**A new scheme to support early career researchers is being funded by the MND Association and co-ordinated by MND Scotland. This pre-fellowship scheme is a positive step towards delivering on one of the aims of the UK MND Research Institute – to train future leaders in MND.**

It is designed to develop the researcher's skills before they apply for a fellowship programme. Researchers applying for fellowships, such as our Lady Edith Wolfson Fellowships, need data to show the full potential of their work. The scheme offers young scientists the opportunity to gather this data by funding their work for 12-18 months.

Three pre-fellowships have already been awarded to early career researchers who will investigate a wide range of topics, from developing potential drugs to clarifying possible sub-groups of MND. One of the researchers awarded a pre-fellowship is Dr Emily Carroll from the University of Oxford.

Emily said: "Funding schemes such as the MND Association pre-fellowship are really important for early career researchers. Full fellowship applications

are competitive and require sufficient pilot data to support your research plan, which takes time to acquire. Given this, funding which bridges the gap between finishing a PhD and applying for a fellowship is key to allow early career researchers time to generate sufficient pilot data for a full fellowship application."



*Dr Alannah Mole*

These awards will also boost collaboration between research centres in the Institute and provide a stepping stone to encourage scientists to dedicate



**This pre-fellowship will provide a unique and exciting opportunity to research some of my own ideas, while benefitting from the advice, support, and expertise of established researchers in an amazing environment.**

their careers to MND research, as Dr Alannah Mole, pre-fellow at the University of Sheffield, explains.

"This pre-fellowship will provide a unique and exciting opportunity to research some of my own ideas, while benefitting from the advice, support, and expertise of established researchers in an amazing environment. This time will also be particularly valuable in allowing me to gather preliminary data in preparation for fellowship applications, where I can pursue ideas further and ultimately work towards becoming an independent MND researcher."

## The Rob Burrow MND Rose raising funds for MND



**A very special rose made its debut at Hampton Court Flower Show in July. It is special for two reasons, the first because it's named after one of our patrons, rugby legend Rob Burrow MBE, and the second because it's raising vital funds for the MND Association.**

The rose is now available to buy online, with £2.50 donated to the Association for every rose sold. Fittingly, the first garden the rose was planted in was Rob's. Phillip Harkness, Chairman of the Harkness Rose Company, visited Rob and his family at their home. Rob's children got stuck in, helping to plant the first ever Rob Burrow MND Rose.

Phillip said: "This is a cause close to my heart so I'm delighted to be bringing this variety to market. This beautiful saffron yellow rose has a compact, bushy growth habit making it suitable for both small and generous spaces. It will also thrive in a large pot."

**The rose is available to order now at [www.roses.co.uk](http://www.roses.co.uk) or [www.worldofroses.com](http://www.worldofroses.com)**

# Exercise avoider completes London Marathon



Above left; race day, top right; first run, bottom right; after-race celebration

“  
When you realise that every competitor is running for someone or something, and often fighting battles that most of us couldn't imagine, it puts everything into perspective. To be part of that, raising money for the MND Association, will always be something that I am immeasurably proud of.”

**Describing himself as ‘an obese London wine merchant with a disdain for exercise’, Gareth Birchley exceeded all expectations when he not only completed the London Marathon, but did so as the top male fundraiser, pledging over £271,000 to the MND Association.**

Gareth describes how he was ‘coerced’ by now retired England bowler Stuart Broad on a night out. Instead of backing out quietly the next day, Gareth filled in the forms and started exercising for the first time in over a decade.

Gareth said: “Almost a year ago, after some poor liver test results, I drunkenly agreed to run the London Marathon in order to force a lifestyle change and raise a significant amount of money for a good cause.

“As an obese London wine merchant who had not partaken in any form of exercise in over a decade, it was an uphill challenge. I started back in the summer of last year, unable to run continuously

for one minute, with 26.2 miles as the end goal on 23 April 2023 in front of 750,000 spectators.

“True to form, this was, it seems, not enough of a challenge, so I additionally committed to raise £100,000 in the name of the Broad Appeal to support the work of the MND Association. The Broad Appeal was co-founded by my friend and ex-professional cricketer, Stuart Broad, following the death of his step-mother, Miche, from this horrific illness.”

As a buying director for fine wine merchant Burns & German Vintners, Gareth used his connections to maximise his fundraising efforts. He organised an online food and drink auction, with some sport and travel prizes. He said: “I’ve been totally overwhelmed by the generosity of so many wineries, restaurants and friends who have contributed so many ‘money can’t buy’ lots for people to bid on, for such a worthy cause.

“In a way, I feel this is my magnum opus... the culmination of nearly two decades in

the wine industry in auction form. There are tastings, dinners, winery visits, trips and of course, uber rare bottles – most of which are once in a lifetime experiences.”

Gareth’s training paid off and he completed the marathon in what he described as: ‘a time long enough to savour every minute’. He went on to say: “I absolutely loved the race. To be honest I expected to go to a few dark, reflective places in my mind as I had done on my training runs in the winter wind and rain, but the crowd just simply didn’t let that happen. The whole thing was so up-beat, high energy and supportive. It was so humbling to see London, and indeed Londoners, in the most wonderful light.

“When you realise that every competitor is running for someone or something, and often fighting battles that most of us couldn't imagine, it puts everything into perspective. To be part of that, raising money for the MND Association, will always be something that I am immeasurably proud of.”

# The power behind our campaigns is a special group of people

**Securing Government funding of £50 million for MND research, achieving reform to the Special Rules for Terminal Illness process, and persuading councils to reduce and remove means-testing for Disabled Facilities Grants are just some of our recent campaigning successes.**

The power behind every one of these campaigns was a very special group of people living in England, Wales and Northern Ireland. A group united by one goal – to improve the lives of people affected by MND. Our campaign volunteers are at the heart of our campaigning work. Here, we shine a spotlight on their incredible work, so you can see how their relentless determination is making a difference.

## Reaching out to councils

Volunteers Cris, Debbie and Vincent have been working with councils in the North West to improve Disabled Facilities Grant processes for people with MND. This is part of our *Act to Adapt* campaign. As a result Sefton Council has now changed its policy and removed means testing up to £30,000 and to fast track people with MND. There have also been positive outcomes in Wirral, while campaigning continues in Halton.

## Championing the MND Charter in Wales

Christine in North Wales successfully persuaded Flintshire County Council to pledge its support for local people affected by MND, by adopting the *MND*

*Charter*. She set the ball rolling with a meeting with local councillors.

## Speaking out for MND carers

In Devon, Ian posts weekly poems on social media to raise awareness of MND. He has recently taken to Facebook to promote the right to a carer's assessment as part of our *Support MND Carers'* campaign.

## Sharing stories to improve care

In Surrey, Shahla became a campaigns volunteer after her husband, John, was diagnosed with MND. Since he died last year, Shahla has been working hard to make sure others have better co-ordinated care. To highlight this need, Shahla has shared her and John's story with her local Integrated Care Board, the North West Surrey Alliance.

Shahla said: "I wish to thank the North West Surrey Alliance for the amazing support and enthusiasm they've shown since I initially contacted them. I reached out to them in desperation and they responded brilliantly! Occasionally it just needs a flicker to get everyone's attention and unify aims. This is my vision."

## Could you be a campaigns volunteer?

Whether you have a little time or a lot, as a campaigns volunteer for the MND Association you can make a big difference. You'll be joining an amazing group of people and will get a lot of support from our Campaigns Team.



Our *Campaigning toolkit*, available to all campaign volunteers, includes clear guidelines, tips and ideas for making the most of campaign opportunities from attending and contributing at public meetings to securing media coverage for an event.

For more information please see [www.mndassociation.org/campaignsvolunteers](http://www.mndassociation.org/campaignsvolunteers) or contact us on [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org) 01604 611681.





# MND Care Centre and Network Day

## Sharing knowledge across the network

**The Association funds roles at MND Care Centres and Networks to improve the support and co-ordination of services for people living with MND across England, Wales and Northern Ireland. Our Care Centres and Networks were also created to help make care equitable, so that wherever people live, they can access co-ordinated, multidisciplinary care.**

At multidisciplinary clinics, people with MND can see all the professionals involved in their care in a 'one-stop shop'. Another advantage is that the professionals in the clinic are able to share knowledge and discuss care management together.

A few years ago, we decided to extend this sharing of knowledge within centres and teams across our entire care centre network, by bringing everyone together at an annual event.

This year, the Association's annual Care Centre and Network Day took place on Wednesday 21 June, with the theme *Partnerships for success – the way forward for MND care*. It was the first in-person event held since 2019, providing an opportunity for directors and co-ordinators from the 22 MND Care Centres and Networks to learn, share expertise and focus on improving care for people living with MND.

For professionals working with a relatively rare condition, it is even more beneficial to meet up with others and feel part of a much wider movement, as Colette Bloomfield, MND Care Centre Co-



Colette Bloomfield



**I really enjoyed linking in with the engaged and passionate MND professionals community. It felt great to be a part of that crowd.**

ordinator, Neurosciences Nurse, at Barts Health MND Care Centre explains:

"I really enjoyed linking in with the engaged and passionate MND professionals community. It felt great to be a part of that crowd."

The day included talks on the latest



Rebecca Hesketh



**You all worked very hard which was very much appreciated, and it made a fantastic day. I hope to get invited to the next one.**

developments in MND care including launching a new optimal pathway for MND (see page 26), discussions on new and emerging treatments in MND and workshop topics such as carers needs, building a business case and best practice in multidisciplinary team working.

Through sharing our collective expertise and experiences, we can continue to ensure MND Care Centres and Networks remain at the forefront of clinical practice and driving up standards of care for people with MND. The majority of those attending (98%) confirmed they would like to attend future events, like Rebecca Hesketh, MND Specialist Nurse at Lancashire and South Cumbria Care Centre who said: "I really enjoyed meeting with others. You all worked very hard which was very much appreciated, and it made a fantastic day. I hope to get invited to the next one."

The MND Association will continue to find opportunities for collaboration and sharing knowledge across clinical teams to transform the lives of people with MND, by helping to manage symptoms and improve overall quality of life.



Professor Ammar Al-Chalabi, Director of King's MND Care and Research Centre, and one of the speakers at the Care and Network Day



Nick Goldup, Director of Care Improvement at the MND Association



**PROMISE 5**  
WE WON'T REST UNTIL  
**NO ONE FACES MND ALONE**

## Reaching out in different languages



**We are expanding our support for people affected by MND who don't speak English. Non-English speakers will be matched with staff or volunteers who have compatible language skills.**

Following the matching process, they'll be invited to join a telephone call where staff and volunteers will be able to gain an understanding of their needs, and explain what support is available from the Association. If you have language skills (you don't need to be fluent) and would like to help, contact [inclusion@mndassociation.org](mailto:inclusion@mndassociation.org)

If you need to speak to MND Connect or our Benefits Advice Service, but find English difficult to understand, we can arrange for an interpreter to join your telephone call. Please remember that health and social care professionals may also be able to arrange for an interpreter to help you at future appointments with them.

### Care information in other languages

We provide some of our care information leaflets in a range of languages. You can download them from our website [www.mndassociation.org/language](http://www.mndassociation.org/language) or contact [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) for printed copies.

## Surabhi – supporting people with MND

Started by a group of friends to promote Indian arts, Surabhi is an Indian charity based in South Yorkshire. Surabhi raises funds for a number of charities in India and the UK, and this year, we were delighted Surabhi decided to support the MND Association, with £8,000 raised at a recent dinner and concert.



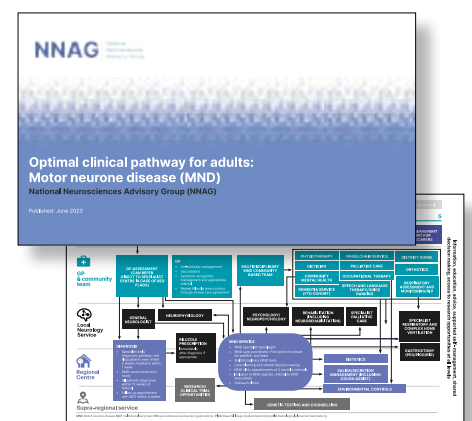
Members of the Indian arts charity Surabhi, presenting a cheque to John Gillies-Wilkes, Head of Inclusion and Wellbeing for the Association pictured third from the left

## A pathway to better care

**MND is a complex disease to manage, getting ever more complex as the disease progresses. A new clinical pathway provides a blueprint on what good MND treatment, care and support looks like from initial presentation and diagnosis to ongoing management and end-of-life care. We hope this pathway will drive up standards of care for every person living with MND.**

Published by the National Neurosciences Advisory Group (NNAG), the *Optimal clinical pathway for adults: Motor neurone disease (MND)* was developed by MND clinical experts, with the support of the MND Association, the Neurological Alliance and people living with MND.

We hope the evidence-based information will equip commissioners and planners with the knowledge to improve MND services locally and ensure they meet the needs of people



living with MND. We know people with MND who receive co-ordinated, multidisciplinary support are more likely to have an improved quality of life, fewer unplanned hospital admissions and increased survival. This pathway strongly emphasises the importance of a co-ordinated, multidisciplinary approach to MND care, and provides the steps in a patient's journey to deliver it.

# Waving the flag for MND at Manchester Pride



By being at Pride, we're sending a positive message and showing everyone here, and on social media who are affected by MND, that they will be welcomed both by their local branch and also the MND Association regardless of their sexual orientation or gender identity.

Paul Golds, Manchester and District Branch member

## The MND Association's Pride Network attended Manchester Pride in August alongside people living with and affected by MND, and members of the Manchester and Wirral branches.

Research shows LGBTQ+ people are less likely to seek help and support from health and social care services and organisations due to fear of discrimination. Our attendance at the event in Manchester, home of TV soap *Coronation Street* which is currently running an MND storyline (page 8), helped reinforce the MND Association's position as a welcoming and inclusive organisation to all communities. It can and does affect anyone, regardless of their sexual orientation or gender identity.

Staff and volunteers held up placards with a QR code linked to a webpage where people could learn more about MND, the Association, and the Manchester Branch, and make a donation if they wanted to show their support.

Speaking after the event, Paul Golds, member of the Manchester and District Branch said: "By being at Pride, we're sending a positive message and showing everyone here, and on social media who are affected by MND, that they will be welcomed both by their local branch and also the MND Association regardless of their sexual orientation or gender identity.

"While I've lost my mum to MND, I've found a new family through the MND community. It's so important that this is open to anyone affected by MND. It was also fantastic to see such a huge turnout today with so many other charities, clubs and local groups here."

If you're interested in joining the MND Association's Pride Network please email [pride@mndassociation.org](mailto:pride@mndassociation.org)



# Passion for golf turned into pounds

**Graham Robson, a retired teacher from Brentwood, Essex, was diagnosed with MND in 2022. Until then, Graham was very active and regularly played golf and cricket with friends. Following his diagnosis, Graham set himself an ambitious target to raise £10,000 for MND research and to support people living with MND in Essex.**

On Friday 16 June, 88 players and four assistants took part in a day of golfing at Orsett Golf Club. The players, together with donations from others who couldn't join them on the day, helped to raise an impressive £11,572.

After a bacon roll and swift start at 11am, 18 teams took on the Putting Competition with each team challenged to get round a nine-hole course in as few putts as possible. Having suitably

warmed up, each team proceeded to their allocated starting hole on the full 18-hole course for the main competition of the day.

Prizes were up for grabs for the individuals and teams who came first, second and third. In addition, there was the opportunity to 'Beat the Pro' and win bragging rights if you managed to get your ball closer to the hole than the professional golfer managed.

Following the golf everyone enjoyed a two course meal with the day ending with the prize giving, a raffle, and an auction.

Graham thanked everyone, particularly the helpers, for making the day so special and for enabling him to reach his target of £10,000.

Graham said: "I'm an outgoing person and I will continue to do what I can. I will



Graham pictured right with team member

continue to play golf, and I will do my very best to live life to the full. I wanted to raise money to contribute to research and to help others living with MND. I'd like to thank everyone for supporting the golf day, particularly the helpers, for making the day so special. It's wonderful that together we raised so much money for the charity."

## YOUR STORIES

# Open day for supporters

**Chair Jan Fisher shares her reflections on the South West Wales Branch's first open day.**

**We had noticed our members and supporters were showing an interest in knowing where their donations were being used and what was happening in the world of research.**

So our committee decided to hold an event that would showcase how supporter's donations are used in the area, provide updates on care and campaigning, and give an update on research and development.

On Saturday 29 July at Morgans Hotel in Swansea we held our first South West Wales Branch open day, with the help of MND Association staff.

Clare-Ann Magee, Head of Regional Care Partnerships, gave an update on what is happening in the Care sector, especially in Wales with Sarah Lowther, Area Support Co-ordinator for South West Wales updating further on what is happening in our branch area.

Millie Jenkins, Senior Policy and Public Affairs Adviser – Wales, gave updates on ongoing and upcoming campaigns and spoke about events and support in the Senedd.

Richard Shackelford, Regional Fundraiser for Wales, spoke about charity and fundraising and afterwards awarded a certificate celebrating ten years of fundraising to Justin Hostettler-Davis, a branch member who has raised in excess of £180,000.

Sian Guest, Public Affairs Manager – Westminster and Devolved Nations, gave an update on research and development.

Dr Owen Peters, UK Dementia Research Institute, Cardiff, gave a talk on what DNA can tell us about MND, using genetics to understand the causes of neurodegenerative disease and develop MND therapies.

This was an informal event that made for an enjoyable and informative afternoon and our thanks go to the speakers who attended to help make the day a success.



Dr Owen Peters addressing supporters of the branch open day

# Support MND Carers campaign

## Engaging local authorities and councillors



Top row: Cllr Ian Roome (Lib Dem) with Niall (Senior Campaigns Adviser), Cllr Nate Higgins (Green), Cllr Anna Smith (the one in mask) (Labour), under is Cllr Alison Holt (Lib Dem), then Amaani (Senior Campaigns Adviser) Bottom row: Cllr Fran Whymark (Conservative), Cllr Richard Kemp CBE (Lib Dem), Cllr Suzy Horton (Lib Dem), Cllr Frank Biederman (Independent) and Cllr Sarah Rouse (Independent)

**We recently launched a new phase of the Support MND Carers campaign, with a strong focus on engaging locally. We kicked off by attending the Local Government Association (LGA) Conference in July, where we had the opportunity to connect with councillors and local authority staff.**

During the conference, we spoke to over 80 people, including more than 60 councillors. Our message was clear: MND carers need to be better supported.

Carer's assessments are one way of getting unpaid carers the support they need. Assessments provide an opportunity to ensure the right support is in place for each carer, signposting to services like counselling or benefits advice, and helping to plan respite or emergency care.

But nearly eight out of ten unpaid carers

**Eich hawl i gael asesiad gofalwr**

Am hysbysu eiddoedd i MNDAssociation.org/CarerSupport

---

**Your right to a carer's assessment**

For more information visit [MNDAssociation.org/CarerSupport](http://MNDAssociation.org/CarerSupport)

<p><b>What is a carer's assessment?</b></p> <p style="font-size: x-small;">A carer's assessment enables you to tell adult social care services how your caring role could be made easier.</p> <p style="font-size: x-small;">You have a right to a carer's assessment whether or not you live with the person you support. You may provide care full-time or part-time, or combine care with paid work.</p> <p style="font-size: x-small;">The person you support doesn't need to have had a social care assessment.</p>	<p style="font-size: x-small;">You should be offered an assessment once you have been identified as a carer, or you can ask for one. Contact your local authority or, in Northern Ireland, your local health and social care trust.</p> <p style="font-size: x-small;">The assessment does not judge your capability as a carer, but allows you to review your caring role.</p> <ul style="list-style-type: none"> <li>Do you need help with the services that could support you?</li> <li>Are you willing and able to carry on caring?</li> <li>Can you continue to give increasing levels of care?</li> </ul>
<p style="font-size: x-small;">An assessment will help you find out about:</p> <ul style="list-style-type: none"> <li>care services, benefits advice and local voluntary organisations</li> <li>planning for respite, urgent or emergency care</li> <li>assistance with travel</li> <li>how to maintain your own interests, studies or activities while caring</li> <li>suggestions for counselling or support groups.</li> </ul>	<p style="font-size: x-small;"><b>siŋtu i gael gwyaed am:</b></p> <p style="font-size: x-small;">• fudd-deddfau a sefydliadau eraill neu ofal trwm</p> <p style="font-size: x-small;">• gwybodaeth neu wellfgoedddau i'w rhoi gwybodaeth</p> <p style="font-size: x-small;">• gwybodaeth neu wellfgoedddau i'w rhoi gwybodaeth</p>

[www.mndassociation.org](http://www.mndassociation.org)  
 MND Association of Wales  
 100, The Quadrant, Cardiff, CF10 1AT  
 Tel: 0300 300 3000  
 Email: [info@mndassociation.org](mailto:info@mndassociation.org)  
[www.mndassociation.org](http://www.mndassociation.org)

Infographic available in English and Welsh

of people with MND haven't received a carer's assessment and 40% are unaware of their right to a carer's assessment.

At the LGA Conference we asked

councillors to write to their cabinet member responsible for carer's assessments to highlight these findings and work with us to improve access to, and the adequacy of, carer's assessments locally.

You can help too! We've created a handy infographic to help highlight people's right to a carer's assessment. Help us raise awareness by downloading the infographic and sharing it on social media, local notice boards or anywhere else you think may be useful.

If you'd like to get more involved in the Support MND Carers campaign, please email [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org) or visit [www.mndassociation.org/supportmndcarers](http://www.mndassociation.org/supportmndcarers).

Unpaid carers play a vital role in the care of people with MND. Let's make sure they're better supported.

# £100K rowing challenge for Pete

## A special tribute

**Friends of Pete Bellenger, a chemistry teacher who died earlier this year from MND aged 48, wanted to do something special in his memory. While at university, Pete rowed for the Oxford Lightweights crew – so his friends decided a rowing challenge was the most fitting tribute. But it could be no ordinary row, it had to be something special.**

After Pete's funeral a group of friends formed 'Team Pete' and settled on the idea of '£100K for MNDA'. Chris Webster, Pete's friend and colleague from Brighton College, said: "When we floated the idea of the £100K for MNDA Henley to Oxford row, we had three goals. Firstly to involve Pete's family in a fitting memorial with the New College and rowing communities, where he spent some of his happiest times. Secondly to raise funds for the MND Association which works tirelessly to support people with MND. And thirdly to set the precedent for a future 'Team Pete' to take up the Peter Bellenger Memorial Challenge."

'Team Pete' smashed its £100,000 fundraising target – the totaliser now stands at £125,000. Chris said: "Never could we have imagined the time, cheer, love, laughter and know-how from so many people, which made this event a reality. With Pete's family encouraging us and waiting for us at the finish line, our first goal was heart-warmingly achieved. It was the perfect tribute to him. The *Top Gun* theme tune, which heralded



Members of 'Team Pete' taking part in the rowing challenge

the crew's arrival at the finish line, and Sara Cox playing Dario G's *Sunchyme* on Radio 2 for Pete and the team, will always remind me of this special day.

"Neither could we have imagined the generosity and support from people. While '£100K for MNDA' had a ring to it, many of us worried that such a large sum would overshadow our main goal of commemorating Pete. But incredibly, nearly 600 people contributed over

£125,000. We want to thank everyone who supported us. Together we've made a significant contribution to supporting ground-breaking research into drugs, as well as helping the charity to support people with MND.

"In his acceptance speech for his teaching award and in his blog *No Ordinary Hope* Pete talked of his wonder at the love and support he discovered when he was at his most vulnerable. For many of the crew, this event has been a lesson in exactly that wonder. That life is not always about being the biggest or the best; that there is a transformational power in a community brought together by generosity, kindness, humility, laughter and big-heartedness. For many of us in 'Team Pete' – rowers, organisers, supporters and donors – that's the 'no ordinary hope' Pete has left us with.

"And, as for our third goal to set the precedent for a future 'Team Pete' to complete the Peter Bellenger Memorial Challenge – £100K for MNDA, we can't wait to cheer on the new crew of '£100K for MNDA' rowers."

Thanks to the Garfield Weston Foundation for their generous gift of £50,000 to Pete's rowing challenge.



“  
Together we've made a significant contribution to supporting ground-breaking research into drugs, as well as helping the charity to support people with MND.”

# bakeit!

## Get baking as every penny counts



**It's that time of year again when 12 amateur bakers fill our screens each week, bidding to become the winner of Channel 4's *Great British Bake Off*. You might not have the skills to compete for the coveted title yourself, but you can still use your baking talents to raise money for the fight against MND.**

Get together with friends, family, colleagues or the local community and host a bakeit! event. Whether it's a low-key coffee morning with a few friends, a bake sale at work or an afternoon tea party for all your neighbours – every penny you raise will make a difference.

When you sign up, you'll receive a fundraising pack with everything you need to host your event including a bakeit! guide jam-packed with tips and advice to make your event a showstopper, cake cards to label your masterpieces and a cup cake sweepstake to help raise extra funds.

Visit [www.mndassociation.org/bakeit](http://www.mndassociation.org/bakeit) and sign up for your free bakeit! pack today. On your marks, get set...bake!

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[www.wheelchaircars.co.uk](http://www.wheelchaircars.co.uk)

# Spotlight on Inclusion

**As reported in the last edition of *Thumb Print*, we are continuing to ensure 'inclusion' is the golden thread running through our work, so that our services are fully accessible to everyone affected by MND.**

## **Bringing communities together**

After noticing a number of people living with MND were also veterans, Dawn Pond, an Area Support Co-ordinator, set up a veterans support group. Facilitated by a former army sergeant, the group met for the first time in August. The veterans welcomed the opportunity to come together and share experiences.

One of the new members said: "I have been diagnosed for over two years and I haven't wanted to join a group before, but seeing as this was ex-military I felt I wanted to join and was so pleased I did. I have gone from flying Apache helicopters to flying around

in my wheelchair." This group will now meet monthly. If you would like more information about the group, please contact dawn.pond@mndassociation.org

We also have two network groups open to staff, volunteers and people living with MND:

**EMBRACE** for members of the Black Asian and Minority Ethnic community.  
Email: EMBRACE@mndassociation.org

**PRIDE** for the LGBTQIA+ community.  
Email: PRIDE@mndassociation.org

Many of us belong to specific communities. These may be related to your work or profession, faith, gender identity or sexual orientation. If you are a person living with MND and interested in talking to others living with MND from the same community as you, contact inclusion@mndassociation.org



**I have been diagnosed for over two years and I haven't wanted to join a group before, but seeing as this was ex-military I felt I wanted to join and was so pleased I did.**

## **Less visible disabilities and conditions:**

We would love to hear from you if you are neurodivergent, living with a mental health challenge or any other less visible condition. Please contact inclusion@mndassociation.org

## Allora 3

### Straightforward Communication

Visit [www.jabbla.co.uk/allora-3](http://www.jabbla.co.uk/allora-3) for more info or to arrange a free trial.





# The Ultra Challengers

## Record numbers join #TeamMND



Clockwise from top left: Alison Roff and team; Ricky Haynes; Anna Crombie and Antonia Lloyd; Sean Quantick with his dad;

“  
There was a lovely atmosphere among the MND community, and we even met people dog-walking enroute who stopped to thank us and had their own stories of people they'd lost.”

### Record numbers of people have joined #TeamMND to go the extra mile for the MND Association. Or to be more accurate, many, many extra miles.

So far this year, 300 people have signed up to test themselves in a series of endurance events taking place in some of the UK's most scenic locations, including the Isle of Wight, the Lake District, the Jurassic Coast and the Cotswolds. Together they have raised a staggering £166,000.

Ultra challenges have soared in popularity in recent years, with a growing number of people wanting to take on endurance events. The Ultra Challenge event series includes 14 events across the UK where participants can choose to walk, jog or run 25, 50 or 100km.

Antonia Lloyd and Annie Crombie joined the Cotswold Way Challenge in June, raising money in memory of Antonia's mum who had MND. Antonia said: "There was a lovely atmosphere among the MND community, and we even met people dog-walking on route who stopped to thank us and had their own stories of people they'd lost."

For some it's about taking it steady and simply reaching the finish line. For others it's about beating the clock. Ricky Haynes took part in the full distance of the Jurassic Coast Challenge, running all 100km in 13 hours and 40 minutes. He finished 13th of 765 participants and said: "I was literally lost for words at how well it went, I'd never completed a distance like that before. I was inspired to take part after reading Rob Burrow's autobiography. He said life should never be taken for granted and we should seize opportunities whilst we can." Ricky raised an incredible £1,653.

Sean Quantick has taken on not one but two challenges this year – the Jurassic Coast Challenge in May and Thames Pathway Challenge in September. Sean said: "I'm doing it in support of the North Wiltshire Branch which has been supporting my dad and the whole family since his diagnosis in 2021. The Jurassic Coast was incredibly difficult, and the warm weather made it even more exhausting, but I'm really pleased with my finishing time of 22 and a half hours. I enjoyed a couple of weeks rest before starting training for the next one."

The varied distances make the events perfect for a team challenge. Alison Roff and friends from Slough Hockey Club joined the Easter Ultra Challenge back in April, taking on either 25 or 50km around Windsor and the surrounding countryside. They wanted to show their support for their friend Deb who has MND. Alison shared: "Watching Deb go from being a fit, healthy and active individual who lived life to the full, to having no movement in her arms, legs and torso and being on 24-hour breathing support is heart-breaking. We wanted to raise as much as we can for the MND Association which continues to support families like Deb and Ray, and which is at the forefront of the scientific research that aims to one day find a cure for this horrific disease." The team raised over £6,600.

The series finale is the Halloween Walk, which takes in London's scariest streets and historic haunts over a 10 or 25km route after dark. Spooky costumes at the ready, the event is perfect for a memorable night out and is a great way to raise money for the fight against MND.

Inspired? Join us for an Ultra Challenge by visiting [www.mndassociation.org/ultra](http://www.mndassociation.org/ultra)

# 20 years of fundraising from the Thomas family

**A much-loved mum and nan, Joyce Thomas was the heart of the family, until she sadly died just seven months after being diagnosed with MND in 2002. When Joyce received her diagnosis, the family started fundraising. That was over 20 years ago and the family hasn't stopped since, raising over £100,000. Now three generations of the family are keeping the memory of their nan alive, as Lisa Thomas, Joyce's granddaughter explains.**



Members of the Thomas family

My sister Nicole and I were in our 20s when Nan received her diagnosis. Nicole took care of Nan's medical care during the day, particularly around the PEG, while I took care of the rest to plug the gaps in Nan's minimal care package.

"The whole family rallied round and looked after her at home. Back then there were no breathing machines, no grants, no voice banking. Nan lost her speech after three months. We'd have given anything to have heard her voice a little longer.

Nan was the most special lady. She wanted nothing more than her family around her. She was one of life's beautiful souls. As she got to the last stages of MND, she still showed so much heart. And as she took her final breath, her thoughts were with her loved ones. One of the last things she ever did was look at Grandad and then back at me and my sister. It was

clear she was asking us to look after him.

Back then, MND was little known and there was minimal support, but the Northampton Branch was amazing with our family, so we very quickly started fundraising for them. Before Nan died my dad, Dill, and uncles Vince and Nigel and their wives, organised a golf day. It was such a huge success, and they've since done another 20. The annual golf day now



300 holes golf event in July

is like our Christmas Day and everyone takes part.

Fundraising has become part of our lives. All of the family get involved. We're organising a spectacular ball later in the year, I'm doing the London Marathon and the Run60 challenge. My cousins Joe and Charlie cycled 360 miles around Snowdonia and North Wales. My uncle Vince organised the 300 holes golf event in July. My cousin Laura ran the Brighton Marathon, and Joe did the Brecon Beacon Trek – The Fan Dance – which we think is the hardest challenge so far.



Joyce Thomas

We're as motivated to raise money for the MND Association now as we were back then. Our family are good friends with Jan Warren, Chair of the Northampton Branch. I remember a few months back when Jan told me about a grant they weren't able to fund. That was a pivotal moment. We knew then our contribution could never stop. We don't want any family to be told no.

More than anything Joyce wanted the family to be together. I know she'd be especially proud of her three sons and everything they've done in her memory. Nan was special, and even though she is no longer here, she's still at the heart of our family.

**The Thomas family proudly presents their Woodland Masquerade Charity Ball on 20 October, at the Kettering Park Hotel. Please contact Vince 07812 342897 Vince. Thomas@automatech.co.uk or Lisa 07738731469 lisa.thomas33@icloud.com for details.**

# Cycle for Kate

## Rob and Will's 800 mile tribute



Buddy the Bunny and staff at the MND Association's central office welcomed the CycleforKate team during a pitstop between Winchester Rugby Football Club and Doddie Weir's Melrose Rugby Football Club. The team's latest cycling challenge covered 460 miles, raising funds for the Association in memory of Rob Sanderson's wife Kate

**Two life-changing events happened to Rob Sanderson and his son Will in 2014 and 2015 – one devastating, the other uplifting, both connected. In 2014, Kate, Rob's wife and Will's mum, died from MND aged 50, leaving Rob and Will reeling. The second life-changing event was when Rob and Will formed CycleForKate, and set out on an 800 mile journey across France with nine family members and friends. They didn't know it then, but that first trip in 2015 was to become the first of many cycling expeditions in France and across the Rockies of Canada.**

Rob said: "When Kate died, Will and I briefly thought about just readjusting to life. However, MND is such a horrible disease and if no one talks about it not much is going to change. We both agreed we wanted to do something positive to raise awareness and were hoping our bike ride would help others living with MND, their carers and researchers.

Without awareness there is no funding, without funding there is no research, without research there is no cure, without a cure there is no hope. We need to make sure there is always hope."

Since 2015, cycle teams have formed to pay tribute to Kate in the most special way and an incredible £136,000 has been raised in Kate's name through Kate's Tribute Fund. Like many of those affected by MND, Rob has made friends with others in the MND community. Rob said: "I'm so pleased we established CycleForKate, it's led to so many new friendships and mad adventures. I'm also so grateful to everyone who's been a part of it. It's been life-changing for us – but in a good way."

Having clocked up six challenges, Rob is showing no signs of slowing down. He said: "After each one I say to myself this is the last one, but the sense of collective achievement, the fun and laughter, and the funds raised sow the seeds of doubt leading me to think about the next one."



**Without awareness there is no funding, without funding there is no research, without research there is no cure, without a cure there is no hope. We need to make sure there is always hope.**

# Thank you

to all our fundraisers

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

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



£10,000

**Captains Charity Day:** Kevin Ell, Club Captain at Chipping Sodbury Golf Club raised more than £10,000 for the MND Association in memory of his father-in-law, in July. The sun was shining and everyone was in high spirits.



£12,220

**Ray of hope:** The Reading and West Berkshire Branch want to say a huge thank you to the committee which organised the Ray of Hope Family Fun Day and charity walk. The day included a 5km community walk followed by a fete, BBQ, auction and disco raising over £12,200 to support local families in West Berkshire.

**Running man:** Our very own 'running man' Luke Robson completed 365 days of running 5km, finishing on the final day with a half marathon on 31 July. Luke showed incredible determination, running through snow, heatwaves and even tonsillitis to complete the challenge and raise over £22,300



£22,300



£2,300

**Tea and treats:** Ann Franklin's cream tea fundraiser was a storming success, and raised far more than Ann expected. Using the popular combination of scones and shopping, people were able to buy lovely treats along with books, clothes and handbags. Ann said: "I never imagined in my wildest dreams that I would get to that figure."



£6,500

**Race night:** A race night was held on behalf of the North London Branch, for the much-loved Jeremy Bentley, who is living with MND. The event, hosted by Lee Dimmock, Senior Funeral Director of W.H.Putnam Funeral Directors, and his colleague Lorraine Charter, raised an incredible amount for the branch.

If you've been inspired to take part in a fundraising event for the Association, there are loads of ideas to make a difference at [www.mndassociation.org/fundraising](https://www.mndassociation.org/fundraising)



£5,403

**Birthday bash:** Rachael Bacon decided to use a family celebration to raise funds in support of her aunty Jenny, who is living with MND. She held a massive party to celebrate her 50th birthday and her father-in-law Bob's 96th birthday, with 350 of their family and friends. There was a brass band, a rock band, video disco, a bar, hot food and homemade cakes. The double birthday bash raised an amazing £5,403.



£1,250

**Dancing stars:** The North Liverpool Dance Academy's Charity Dance Show raised an amazing £1,250 for the Merseyside Branch. For the academy, the charity show was personal, with Cathi Conroy-Jones, Principal of the Academy and student Maya, both having personal experience of MND.



£7,000

**The Great Ness:** Pete Hawkins took on a gruelling solo cycling challenge from Durness in Scotland to Dungeness in Kent to raise funds and awareness. 'The Great Ness Challenge' was inspired by two friends who recently died of MND. Pete smashed his fundraising target twice over, raising over £7,000



£4,773

**For Richard:** Russell Crocker cycled from London to Paris, raising an incredible £4,773 in support of his brother Richard, who was diagnosed with MND in 2020. Although it was tough, Russell said doing it for Richard gave him the motivation to push through the hard bits. He is completely overwhelmed by the amount of money raised.



**Tireless fundraiser:**

Peter Marrs from the Merseyside Branch has been a member since 1993. He has raised thousands by ensuring the branch's diary continues to be packed full of fundraising events. In his 30 years fundraising, he's organised the Liverpool Anglican Cathedral abseil, walks, cycles, horseracing and quiz nights. A tireless fundraiser, he has dedicated his life to helping people with MND.

**30 years of volunteering:** Margaret Weaver from Great Yarmouth, Norfolk (pictured standing) became a volunteer after her husband Bob was diagnosed with MND in 1991. He died in 1995, but Margaret has carried on his legacy by continuing to raise money and awareness for her local Norwich and Waveney Branch. Thank you for your long years of service to people living with MND.



## Members' letters

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

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

Dear Editor,

**Some of you may have read about my husband Phil Rossall. Indeed, he was in this magazine a number of times over the years with his amazing fundraising challenges.**

My husband, the former teacher, runner, cook, fundraiser, blogger and author battled MND for six and a half years, before his death in February aged 67. Despite becoming progressively disabled, Phil kept busy and in the time he had MND he wrote a blog, two books, broke two Guinness World Records, produced a series of films and raised awareness of MND and over £55,000 for the MND Association. There's little doubt his positive attitude extended his life expectancy – he always had a project on the go.



Phil's two Guinness World Records were for the fastest marathon and half marathon while being pushed by his friend Marcus Green. As Phil became more physically limited, he took on fundraising challenges using blinking, one blink for each step.

It's incredible that despite being 99% paralysed and on a ventilator, in 2020 and



2021 he blinked his way up the Three Peaks, Mont Blanc and Everest. He also blinked his way from John O'Groats to Land's End, a massive 1.4 million blinks. An amazing achievement.

Just before Phil died, he managed to finish a funny novel he'd been writing to raise money for the MND Association, *The Stealth Inspector*. It's a comic novel about a school awaiting an Ofsted inspection and the methods the staff employ to get the better of the inspection team. It's available on Amazon, together with his previous book *Motor Neurone Disease, the*

*Fun Bits*. He'd love the thought of people reading it.

All Phil wanted was to help find a cure for MND and to make people laugh. He remains a total inspiration to us all. Team Phil will continue fundraising and record-breaking challenges and we intend to keep his legacy alive. Next up is a Guinness World Record attempt for the fastest marathon by six people in one costume in the 2024 Manchester Marathon. You'll be hearing more about that later.

*Best wishes, Brenda Rossall*

The MND Association is committed to minimising impact on the environment. As such we have taken the decision to replace the magazine's potato starch outer wrapper, replacing it with a fully recycled paper wrap, 100% sustainable and the most environmentally friendly solution available.

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

Dear Editor,

**I saw a show in San Francisco and one of the songs that stuck in my mind, was 'What you gonna do when the chips are down?' I can still visualise the scenes and occasionally the words ring in my ears. And sometimes it's when the chips are actually down. Whenever it is, I find myself smiling, just recalling what a great time we had.**

Someone told me that when their chips are down, they think of Maria singing, 'My favourite things' from the *Sound of Music*. I have to admit that wouldn't do it for me, but each to their own.

A month or so after our return from San Francisco, my lovely sister-in-law Chris, who we'd stayed with, was diagnosed with terminal cancer and I was diagnosed with MND. It seemed to us that our chips were as far down and out as it's possible to be.

However we decided, independently, that we weren't about to waste time on maudlin thoughts. A few days later Chris began writing what she called 'fridge poems'. Short verses with a positive or humorous message and attaching them with magnets to her rather large American fridge. Spurred on by her spirit of non-compliance, I joined an art club and began painting again.

*Elisabeth 'Lis' Jeffery, who is living with MND*



*Lis pictured right with her sister-in-law Chris*

## About us

### The Motor Neurone Disease (MND) Association


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


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


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

### Social media

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

 [mndassociation](#)

 [mndassoc](#)

 [mndassoc](#)

### MND Connect

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

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

**mndconnect**  
**0808 802 6262**  
[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

### Membership

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

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



## MND Matters

*MND Matters* is the Association's 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](http://www.mndassociation.org/mndmatters) or search *MND Matters* in your chosen podcast provider.

### Episode 29: Cultural challenges with MND

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

### Episode 28: When Eddie met Lesley

Academy Award-winning actor Eddie Redmayne takes the reins as he sits down with the incredible Lesley Connor, an MND Association volunteer whose unwavering dedication has spanned two decades.

### 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.



# Christmas Raffle 2023

**The MND Association Christmas Raffle is now open!**

Thanks to wonderful supporters like you, our last Christmas Raffle raised over £135,000 to provide vital help to people living with MND, their families and carers, and fund research into MND.

We hope you will join in with the raffle this Christmas!

1st prize:  
**£5,000**

2nd prize:  
**£1,000**

3rd prize:  
**£500**

10 x  
Runner-Up  
prizes: **£20**

## Ways to play:

 Online: Scan the QR code or visit  
**[www.mnda.raffleentry.org.uk](http://www.mnda.raffleentry.org.uk)**



 Call: **0330 002 0342**

If you would like raffle tickets to sell to family and friends, please call 0330 002 0342 or email  
**[raffle@mndassociation.org](mailto:raffle@mndassociation.org)**

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

**Closing date: 20 December 2023**

**Draw date: 3 January 2024**



You must be over 18 years of age to play.

Entry is open to all UK residents excluding those in Northern Ireland, Jersey, Guernsey and the Isle of Man.

Please see raffle rules at [www.mnda.raffleentry.org.uk](http://www.mnda.raffleentry.org.uk) for full terms and conditions including information on prize allocation, proceeds and chances of winning.