2024

Impact Report

How **your support in 2024** moved us closer to a world free from MND

mnda
motor neurone disease association

mnda
motor neurone disease
association

Welcome

Sometimes it's only when you see everything written down in one place that you realise just how much activity is happening and how much is being achieved. That's how I felt reading through this, our 2024 *Impact Report*, which I am delighted to share with you.


Tanya Curry,
Chief Executive

We scored a huge win with our *Prescribe Life* campaign around future access to life-saving drug tofersen, we provided more grants to help people day-to-day, and funded new support so people with MND can access the care they need where and when they need it. And then there are the investments we made in new research opportunities, including the first UK-wide drugs platform, a game-changer when it comes to creating the infrastructure our incredible researchers need.

But, of course, there's always more we can do, and we know that. Everyone in the MND community shares a sense of urgency – there is no time to waste. We're using that as our driving force to overcome challenges and not just embrace opportunities but create them.

To do that we're making changes – we're seeking new collaborations and bringing together different stakeholders; we're shouting louder to have our voices heard; we're developing new ways of working to ensure we're delivering what our community needs as fast and effectively as possible; we're drawing courage from our 45-year legacy to be braver and bolder in everything we do, including the way we look and present ourselves. Because that way we can have more impact for our community.

Thank you for playing your part as we strive together for a world free from MND.

WE'RE IMPATIENT FOR NEW TREATMENTS AND A CURE
so we drive research with the greatest promise, invest in scientific talent and widen access to trials for people with MND.


Professor Pietro Fratta


Dr Oscar Wilkins

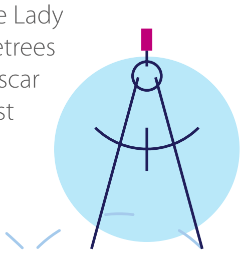
1. Reaching **for a cure**

Precision therapies are a step closer.

In 2022, Association-funded research by Professor Pietro Fratta revealed a damaging change in a gene called UNC13A that occurs in 97% of MND cases.

This discovery paved the way for the launch of a company in 2024, which has attracted over $100 million in venture capital funding, to develop and trial a gene therapy to rescue UNC13A so slowing progression of the disease. That's $100 million of private sector investment unlocked as a direct result of us funding the early work.

Researchers from Professor Fratta's team at University College London (UCL) have also developed a way to target motor neurones being damaged by MND while leaving healthy neurones alone. If effective, this could reduce the risk of side effects, which can be a barrier to developing tolerable drugs. We've awarded The Lady Edith Wolfson Rosetrees Fellowship to Dr Oscar Wilkins, the scientist behind this idea, to drive the work towards clinical testing.



2. Fast-track to **treatment**

MND–SMART
Clinical trials for MND

MND-SMART is speeding up the way treatments are trialled.

+£500k
committed to MND-SMART

MND-SMART is led by the Euan MacDonald Centre for MND Research at the University of Edinburgh. The MND Association funds MND-SMART, alongside MND Scotland and the My Name'5 Doddie Foundation

133	290+
grants* in our research portfolio	researchers* are involved in our research grants

*as of 31 December 2024 see page 11

We've committed £500,000 to MND-SMART, the UK's first MND platform trial, an important step in the creation of a robust, UK-wide research infrastructure.

MND-SMART tests a number of treatments at the same time, comparing them all to a single control group (made up of patients who receive a placebo). This means a higher proportion of the trial volunteers – currently almost 900 people - have access to promising trial drugs, with fewer receiving the placebo. If a drug has no effect it can be removed from the study quickly, and a new drug introduced, speeding up the pace of testing.

MND-SMART is initially trialling repurposed medicines which are safe and already used to treat other conditions. This reduces trial times.

One drug being tested, amantadine, is currently used in Parkinson's, multiple sclerosis and influenza. In 2024, MND-SMART confirmed amantadine appears safe in people with MND. We're now waiting to see if it has a positive effect.

One challenge of repurposing is to identify medicines with the best chance of success. We funded a project that will use a robotic system to screen combinations of thousands of current medicines for their potential to work together. Promising new drug combinations can then be quickly incorporated into the MND-SMART platform. The researchers originally applied for backing through the government's MND Translational Accelerator, but there wasn't enough funding available. We decided the research was too important to delay, so injected a further £400,000 to start the project immediately.

3. Making it easier **to join research**

The foundations are in place for our Research Nurse Network, a £5 million initiative to give more people with MND access to trials.

Specialist nurses will work alongside MND care teams, bridging the gap between researchers and people with MND. This will give more people will have the opportunity to take part in trials and so have access to promising treatments. Ultimately this will accelerate breakthroughs for everyone.

"We know people with MND often spend hours researching and applying to take part in trials. MND Association Research Nurses will do that for them, providing all the guidance and support each person needs."

Sally Hughes, our Director of Services and Partnerships

Ewa Delmaczynska, MND Research Nurse at the MND Care Centre in Birmingham

Supporting talented researchers

Great things can happen when you bring bright minds together.

We provide opportunities for MND researchers to spark ideas and inspiration.

INTERNATIONAL FOCUS

In December, more than 1,200 people from the global MND community gathered at our 35th International Symposium in Canada, with 300 more attending online. With 576 posters and presentations, and researchers from 31 countries, the Symposium is the world's largest scientific and medical meeting focused on the disease. It offers a unique opportunity for researchers to hear about the latest global MND research, share ideas and forge new collaborations.

Of the attendees who shared feedback, 90% said they had made new contacts or kicked off fresh collaborations during the three-day event.

"It reignites that inspirational drive... you go back to the lab, and you're filled with vigour and determination to carry on."

Dr Tobias Moll, MND Association Lady Edith Wolfson Fellow, Sheffield Institute for Translational Neuroscience.

INVESTING IN TOMORROW'S RESEARCHERS

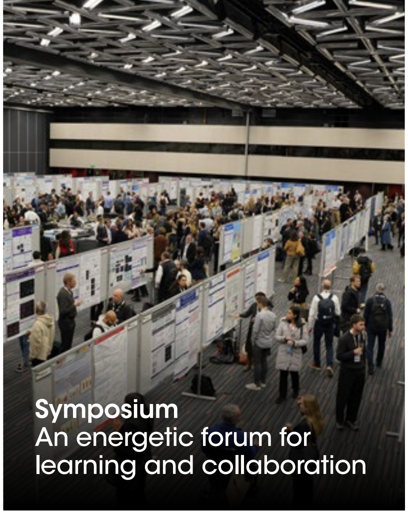
Our investment in researchers at the early stages of their careers continues. The Association's annual MND EnCouRage event enables researchers to connect, learn skills and share ideas among peers and people living with the disease, while learning from experienced researchers. We aim to inspire them to make MND their chosen focus with the hope that, in coming years, they will make important breakthroughs.

"This event is a fantastic opportunity to really get involved in networking... I'm looking for collaboration which is a really key point for me."

Dr Ben Middlehurst, Tenure Track Fellow, University of Liverpool

"Having the opportunity to present to people living with MND is fantastic... getting some perspective back from them about why this is so important and what is that they want to see and what we want to look at in the future. Nothing that we do is of any importance if we can't tell the people that the disease effects what we're doing and how it's giving them hope for the future."

Katie Bowden, University of Sheffield



Symposium
An energetic forum for learning and collaboration

Supporting bright minds

Informing and influencing
Professor Deepak Srivastava, King's College London, addressing the APPG on MND

ASSOCIATION-FUNDED RESEARCH LEADERS

Dr Heather Marriott is the latest early career researcher to benefit from our pre-fellowship scheme, run with the UK MND Research Institute, training future leaders. Dr Marriott will use the funding in an 18-month project aiming to find early indicators of MND progression, which could help to match people with the most suitable clinical trials and, eventually, lead to people receiving treatments earlier.

Dr Heather Marriott

Prescribe life


Tim Wake who is living with MND and has the SOD1 gene

When a decision meant an MND drug may never be available for UK patients, we saw it as a huge injustice.

> *It wasn't just about tofersen. It was about fighting to ensure our community has access to medicines now and in the future. Tofersen just happens to be the first one. There will be more, I'm sure of it.*
>
> **Eleanor Dalley,** who is living with MND (pictured left)

Clinical trials have shown tofersen can slow, and in some cases stop, progression of symptoms in people whose MND is caused by a SOD1 gene variation. It's the first effective treatment for MND identified in decades.

Eleanor Dalley, who is living with MND said: "I was diagnosed in 2019, and confirmed as having the SOD1 gene variation in early 2020. I'm the fourth member of my family to be diagnosed and the only one still alive."

Pharmaceutical company Biogen is currently giving tofersen free of charge to people with SOD1 MND, including Eleanor Dalley. But there's no guarantee that will continue for people who are newly diagnosed.

This raises the real possibility of people in the UK dying for want of a drug readily available elsewhere.

The approval process for tofersen stalled when the regulatory body NICE announced it would evaluate the drug in a way it was bound to fail. NICE refused to budge, so Biogen halted tofersen's application.

We had to act, to convince NICE to reconsider its decision and break the deadlock. We had a strong argument for tofersen as a rare disease drug. So, with Eleanor, we launched a petition to show the strength of feeling in the MND community and beyond.

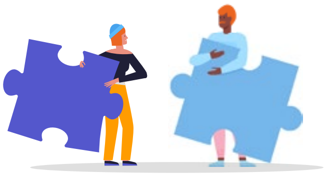
The response was amazing. Within a month, more than 15,000 people had signed the petition. This collective pressure led NICE to think again and, in November, came the announcement tofersen would be evaluated using the rare disease criteria.

In short, we won!

While there's more work to do to get tofersen over the finish line, the whole MND community can be proud of what we achieved together through Prescribe Life.

It's a campaign victory that could literally save lives.

Joined-up care



MND Association-funded care co-ordinators ease the burden of navigating complex care.

They connect NHS services, Association volunteers and staff, and community support services so that people with MND get the right care at the right time in the most convenient place.

We funded five new care co-ordinator roles in 2024. These posts extended support beyond established Care Centres and Networks, reaching more people. More of these posts will be recruited in 2025, to address gaps.

And we launched our 24th MND Care and Research Network, will mean improved support and co-ordination of services for around 180 people living with MND in South West London and Surrey.

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

Kuai Peng, carer for her husband who has MND.

mndconnect

> "Everything had gone from zero to 100, really quickly… and it's because of the advice from MND Connect we were able to get everything ready. They really, really helped us."
>
> **Karen**

This year we expanded our MND Connect helpline to six advisers with a range of expertise and have adjusted the opening hours so we can respond to more calls and emails.

Financial support

MND has a financial burden, from care costs to equipment that's expensive to run. We help.

We provided a record 7,361 support grants,totalling £3.24 million, to 3,148 people and families.

Of this, £1.2million went towards equipment, home adaptations and services such as voice banking. We also provided more than £1.15 million in grants towards supporting wellbeing.

"Without this help, we would be further in debt to the energy company. I am happy with the financial support you have given me and can't thank you enough for that."

Steve Williams who is living with MND

In November, we increased the value of our cost of living support grants from £350 to £500. This was part of the response to our research revealing over 80% of unpaid carers have used savings to pay for day-to-day items. A total of £847,700 was awarded through this fund in 2024.

Steve Williams

Amazing volunteers

EVERY DAY, ANOTHER SIX PEOPLE ARE DIAGNOSED WITH MND.
While we reach for a cure, we support those living with MND now, and work tirelessly for better care.

Association volunteers provide a listening ear and practical support to families in their area.

The MND community continues to be supported by Association volunteers as they have been for more than four decades. **There are now 135 support groups** providing a safe space to meet and talk, many run solely by volunteers.

The latest was inspired by Sam Tooze who has MND. She's worked with the MND Association and The Myton Hospices to open a new group for people in and around Rugby and Coventry. She said: "I was excited to start the group as I felt people … had far too far to travel to get to other support groups in the area. Support groups are great places for people to take time out, relax and chat."

And we have 312 Association visitors offering one-to-one practical support and companionship.

"I have an Association visitor and she's just the best... I can explore things with her before taking them to my family. She'll take the worry away and make phone calls for me, because I struggle with my voice." **Diana Keys**

"I spoke to someone at the MND Association and this guy came round, and what a man! He comes round regularly. He's like a mate. His dad died of MND, so he understands me. It's a really valuable thing the MND Association have done for me." **Steve Williams**

In July, scores of people with MND and their families were supported by volunteers during a memory making day at Peppa Pig World in Hampshire, funded by the charity.

"My mum had a wonderful day with her grandchildren - it's the first time she's smiled in weeks." **Caroline Motson**

The day was just one of the ways we supported 458 families with children and young people facing a loved one's diagnosis. We also provided 712 counselling sessions and 142 memory boxes.

Our Regional Roadshows in the spring brought together people with MND, volunteers and staff to talk, listen and collaborate. And the County Antrim event welcomed a special visitor - our Royal Patron HRH The Princess Royal.

The extra mile for MND

In December, Association patron Kevin Sinfield CBE completed his fifth 7 in 7 challenge. Kevin's awareness-raising endeavours **banked more than a million pounds for MND charities** in memory of his friend and our patron Rob Burrow CBE, who died of MND in June.

Raising standards

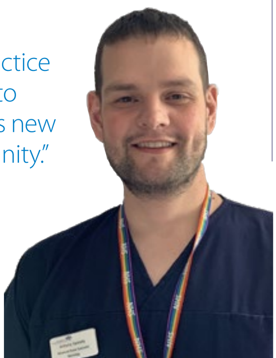
By building skills across health and social care, we're equipping professionals to provide the best care.

Our Community of Practice is a group of health and social care professionals working with us to improve care. We provide resources and learning opportunities to educate and upskill the wide range of professionals involved in caring for people with MND.

Our learning events, from webinars to workshops, attracted over 1,400 professionals in 2024. In June, 135 leaders and co-ordinators from Association-supported services attended our Care Centre and Network Day, to explore priority areas of care through discussion and learning. MND is a complex disease, and our programmes reflect this, covering topics from posture management to anticipatory grief.

"The MND Professionals' Community of Practice Networking Event... is a great opportunity to upskill and learn from each other, taking this new knowledge back to the local MND community."

Anthony Hanratty, Advanced Nurse Specialist and Clinical Lead, Middlesbrough MND Care Centre



Evidence-based support

Research we funded has shown a specific type of psychotherapy can help to improve quality of life.

Acceptance and commitment therapy (ACT) was proven in a clinical trial to help people with MND who are experiencing difficult thoughts.

"[ACT] helped me learn a lot about myself, which in turn helps me cope with what's happening to me"

Jennie, one of the 191 trial participants

We're now funding specialist ACT training for psychologists. As Professor Chris McDermott, joint lead of the trial, says, "While we work hard for a cure, it is essential we support those living with MND now."

This work was the lead topic at the annual Stephen Hawking MND lecture, aimed at healthcare professionals, and which has been watched by 1,500 people.

MND on the **political agenda**

A new parliament is a new opportunity to make change.

During the general election our campaigners urged candidates to sign our MND Guarantee, committing to support people affected by the disease if elected. Eighty-five of our signatories were elected and we're now building closer links with those MPs.

After the election, the All-Party Parliamentary Group (APPG) on MND, for which we provide the secretariat, was re-established. Ian Byrne, MP for Liverpool West Derby, was elected Chair.

"Our job as the APPG on MND is to listen and act on what people want and try to make their lives easier. We need to use our position and influence to drive forward positive change for people living with MND." **Ian Byrne** MP

We formally thanked all outgoing members of the Group, in particular, former Chair Andrew Lewer MP, a passionate and effective advocate.

In November, we met Sir Stephen Timms, Minister for Social Security and Disability, to make him aware carers in the MND community are being impacted by Carer's Allowance overpayments. These often occur due to a carer unwittingly breaching earnings rules, and some are now being forced to pay back thousands of pounds. We will be advocating for MND carers during the Government's review.

In Northern Ireland, following our collaborative campaigning to question the Government's decision to remove the Winter Fuel Payment, a one off payment was made to pensioners. While not a completely successful resolution, this move did help some people with MND.

We also raised the issue of Winter Fuel Payments in the Welsh Senedd, along with the Disability Employment Gap and the implementation of the new Health and Social Care (Wales) Bill, engaging directly during the year with 68% of Senedd members.

Guests and members of the **All-Party Parliament Group (APPG)** during a recent tour of the MND laboratories at Maurice Wohl Clinical Neuroscience Institute in central London

MND HAS A HIGHER PROFILE THAN EVER.
We're building on that to drive change and engage new supporters to power vital research.

A UK first **with powerful impact**

MND takes everything. But it can't take the love inside.

Members of the *Coronation Street* cast involved in the MND storyline which secured several national media awards and nominations

This year we put MND in the spotlight with our first TV advertising campaign for more than a decade. *The Love Inside* was prompted by *Coronation Street's* award-winning storyline portraying character Paul Foreman's journey with MND.

We moved the fiction from the cobbles into fact, by sharing real MND stories. *The Love Inside* featured moving moments from the daily lives of Mike Sumner and his wife Zoe, Mike Small, and Louise Jordan and her husband Rob.

"I'm pleased to see *The Love Inside advert* on TV. Instead of being the hidden disease... MND is now increasingly visible which will help to find a cure and put an end to this awful disease forever."
Sarah Ezekiel who is living with MND

Thanks to our work, and high profile people choosing to share their stories, in July we achieved our highest-ever position in a sector-leading recognition index. With more people understanding MND we have opportunities to engage new audiences to support our work.

Sadly, Mike Small and Louise died shortly after filming. We are grateful to their families for allowing the campaign to be part of their legacy.

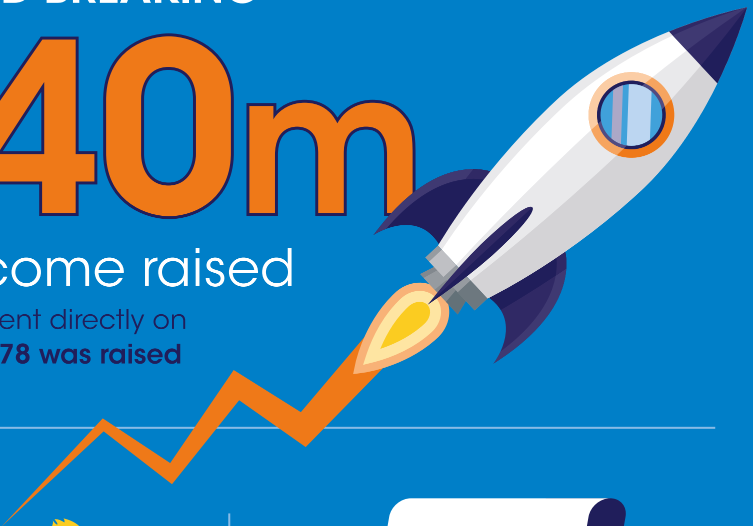
2024: Our year in numbers

A RECORD-BREAKING

£40m

total income raised

For every £1 spent directly on fundraising **£6.78 was raised**



15,000

online signatures received within one week to support our **Prescribe Life** campaign which successfully lobbied for the drug tofersen

12,926

registered Association Members eligible to vote on the direction of our work

£10.5m

donated in legacies

925

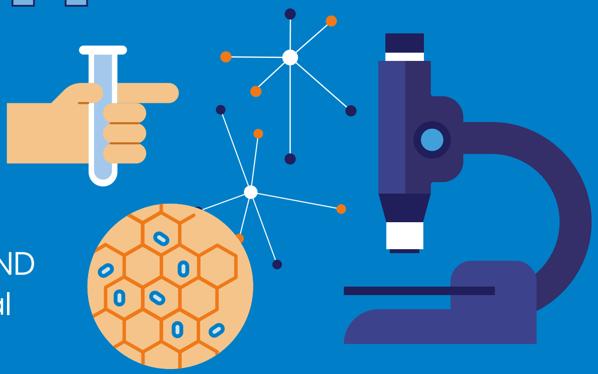
people with MND across England, Wales and Northern Ireland responded to our **My MND My Needs** survey helping to shape our new strategy

78,854

pieces of **MND care** infomation downloaded or sent out

£5m

Funding committed for a new MND Association Research Nurse Network enabling more people with MND to take part in clinical research and trials



87

branches and groups provided information, companionship and support, and raised £3.5m for our work

312

trained Association visitors available to provide one-to-one support to 1,200 people with MND

(Based on activities logged in the volunteer portal)

mnda
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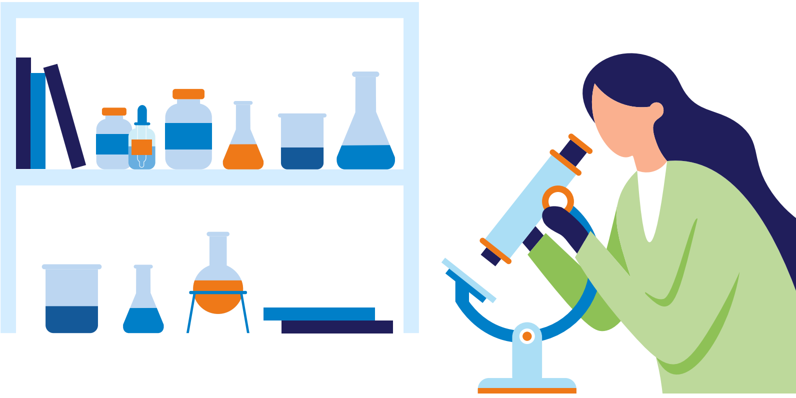
35th international
symposium
on ALS/MND

1,500

delegates from 48 countries attended our **35th International Symposium on ALS/MND** in Canada in person and online



£24m

in funding committed to support 133 research grants (on 31 December 2024). **£9.3 million** of new funding awarded during 2024, including **£8.8 million** awarded to new grants

£3.7m

1,020 cases handled by the Welfare Benefits Service potentially unlocking eligible claims worth £3.7 million

712

Association-funded counselling sessions delivered to children and young people affected by MND

£3.2m

of support grants awarded to **3,148 people** with or affected by MND

Special thanks

Our incredible supporters are fundamental to our impact.

Thanks to you, in 2024 we offered record levels of support services, ran groundbreaking campaigns and awarded more MND research grants than ever.

Special thanks to our patrons, ambassadors and VIP supporters including:

HRH The Princess Royal

Their Royal Highnesses, The Prince and Princess of Wales

The Burrow family

The Dimbleby family

Leeds Rhinos

Stanley McMurtry

Kevin Sinfield CBE, and his 7 in 7 Challenge team

Our trusts and major donors:

Clive and Sarah Burley

Mrs G M Bramall

Gordon and Patricia Gilby

Rita Harding

Simon Sadler

The family of Philip Langsdale

The family and friends of Paul Cook - 'Cookie'

My Name'5 Doddie Foundation

Gareth Birchley, Alice Brandon, James Shaw and the Broad Appeal

The Heaton-Ellis Trust

Alan Davidson Foundation

The Darby Rimmer MND Foundation

The William Brake Foundation

Sam Perkins' charity Stand Against MND

The Freshfield Foundation

The Constance Travis Charitable Trust

The Talbot Trust

BNA Charitable Incorporated Organisation

David Barnett Charitable Trust for its donation in memory of Mark Loveday

Our corporate partners, who collectively helped raise nearly £1.7million, including:

Toyota UK
for extending our partnership for a further two years, having now raised over £500,000

Evoke PLC
for raising £117,000 at Evoke the Stars and committing to a new partnership launching in 2025

Bestway Healthcare
for our continuing partnership, raising £59,000 through 760 pharmacies

Stonegate
for its continuing partnership having now raised over £500,000

Cedar Capital
for joining the fight against MND, raising £45,000 at the Rob Burrow Leeds Marathon

and those who wish their support to remain anonymous.

We would be delighted to discuss how you can help us take the next step forward in the fight against MND, this year and beyond.

Please contact **fundraising@mndassociation.org** if you would like to continue the conversation.

Motor Neurone Disease Association, Francis Crick House, 6 Summerhouse Road, Moulton Park,
Northampton, NN3 6BJ // **Tel:** 01604 250505 // **Email:** enquiries@mndassociation.org

www.mndassociation.org

Front cover image: Vedanth Kumar, PhD student at Sheffield Institute of Translational Neuroscience (SITraN)