



**20
23**

Impact Report

How your support in 2023 is moving us
closer to a world free from MND

Welcome!

At the end of my first year as Chief Executive of this incredible Association, I am delighted to present our Impact Report for 2023, charting the progress and achievements made possible by our members, volunteers, supporters and staff.

It has been a whirlwind year for me. I came with a commitment to always put people affected by MND at the heart of everything we do, and a drive to create an ambitious, bold and brave organisation.

There have been challenges to overcome, there have also been opportunities to embrace and successes to mark. And my biggest learning as we've navigated through all of that is how strong, passionate and dedicated the MND community is.

That community is growing – as awareness rises, research funding increases, new partnerships are developed, and fresh collaborations are founded.

All of this puts us in a better position than ever to push forward towards our vision of a world free from MND. Thank you to every single one of you for working alongside us.

Tanya Curry,
Chief Executive



Research innovation

'A significant milestone in our journey towards an effective treatment for people living with MND'.

That was Chris McDermott, Professor of Translational Neurology at the University of Sheffield, talking at the November launch of the UK MND Research Institute.

The launch marked the official start of a national collaboration of MND research centres, people with MND and charities – including the MND Association. The vision is for the UK to be a world-leading collaborative research hub to, as Professor McDermott, a Co-Director of the Institute, says 'discover new treatment strategies and ultimately new drugs that stop MND in its tracks'.

"An Institute brought together by collaboration to accelerate the arrival of treatments, is just what patients want to see. I am optimistic this will be the springboard to a better future, offering hope to patients and those affected by MND."

David Setters, who has MND, (pictured above)

The Association is committed to both national and international collaborations. In 2023, the International Healey Award for Innovation in ALS (MND) was awarded to a global team which included Professor Andrea Malaspina (University College London) and Professor Martin Turner (University of Oxford). The Association has funded the Professors' work for many years. The award-winning team helped to establish neurofilament light chain protein as a biomarker, which can be used to measure the rate of neurodegeneration in people with MND and to help determine if a treatment is having a beneficial effect in clinical trials. This work played a critical role in the approval of tofersen, a treatment for SOD1 MND, in the United States and the recent approval recommendation in Europe.



Supporting better care

MND is complex – up to 20 different specialists can be needed to support each person with the disease.

The MND Association brings together that knowledge and expertise in the MND Professionals' Community of Practice, a 1,350-strong network of health and social care professionals, including those who work in MND Association funded Care Centres and Networks. Their focus? To improve the care of people with MND.

The Professionals' Community supports continuous professional development by delivering education opportunities, and creating practice tools, resources and information sheets for members. The Community holds online Information and Knowledge Exchanges – where members are updated on current thinking, therapies and research and can share successes, discuss challenges and learn from each other. There is also a vibrant annual face-to-face networking event.



"We had the opportunity to share the importance and value of taking a whole family approach in supporting people living with MND and make others aware of valuable resources and ideas for whole MDT working."

Rebecca Heskeith, MND Specialist Nurse

Campaigning for accessible homes

Not all councils in England have a fast-track process or waive means-testing for people with MND – instead using discretionary powers in relation to accessible housing.

Our *Act to Adapt* campaign is aimed at changing that. We believe everyone with MND should be able to live in an accessible home, without delays or high costs.

Councillors in Hull unanimously passed a motion on improving their housing adaptation

process for people with MND. Councillor Daren Hale suggested some 'processes can delay the help they need'. He reported that in one case a person died just days after the conversion was finished. He said: "We could make so much difference to these people's lives."



Raising awareness

In summer, a much-loved television soap character was diagnosed with MND.

Coronation Street viewers watched Paul Foreman, played by Peter Ash, struggle to understand his symptoms, then face the heart-wrenching diagnosis. The soap's commitment to the storyline has included hours of research with the MND Association team and wider community, including Sam Hayden-Harler, who visited the famous cobbles with his husband James.

"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." **Sam Hayden-Harler**

At the same time, BBC1's hospital-based drama *Casualty* also introduced a character with MND, Gethin, who was at an all-time low following his diagnosis.



"The Association grants have totally changed my life. The ramp allows me to drive my wheelchair outside of the house. So that's no longer a barrier for me getting outside"

Alex Herd, who is living with MND



2023: Our year in numbers



TOTAL INCOME RAISED

£38m

our largest amount ever!

For every £1 spent directly on fundraising, £6.80 was raised



11,885

registered
Association
members



88,110

pieces of MND
Care information
downloaded or sent out



9,392

people accessed our
MND Connect helpline



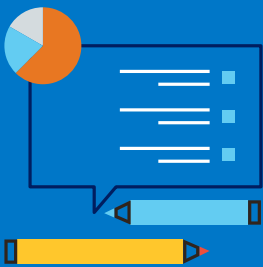
1,037 cases
handled by the
Welfare Benefits
Service unlocked
£3.6million of
eligible claims

£3.6m



357

trained Association
visitors and
co-ordinators
available to provide
one-to-one support to
people with MND



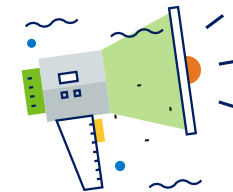
6,123

people with MND have now
signed up to a national
research register and database



3,546

people received
multidisciplinary treatment
at an Association funded
MND Care Centre or
Network (30 Sept)



11,355

campaign volunteers
lobbied with us

915,453

unique visitors to our website

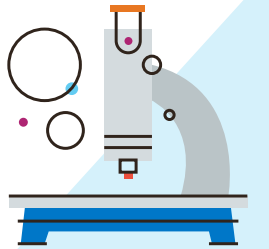


£2.2m

of support grants awarded
to **2,602 people** with or
affected by MND

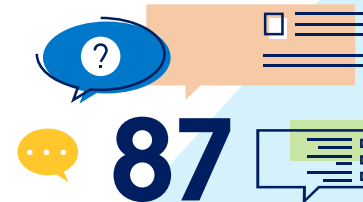


Association funded
counselling sessions
delivered to children
and young people
affected by MND

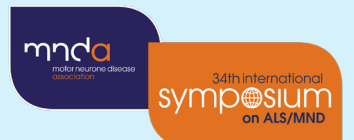


£20.7m

in funding committed to support
109 research grants (at 31 Dec)



87
branches and groups provided
information, friendship and
support across England, Wales
and Northern Ireland

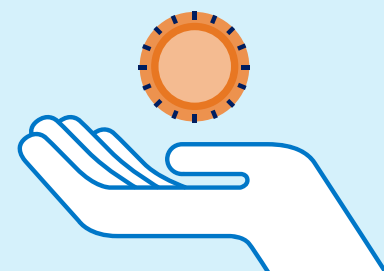


1,300

research delegates from
48 countries attended
our **34th International
Symposium on ALS/MND**
held in Switzerland

£0.5m

committed in joint funding
for MND Smart, a clinical
trial re-purposing licensed
drugs to treat MND with over
500 participants signed up
across 20 UK sites





“Fundraising is so important because that’s the thing that’s going to shift the dial for us. That’s the thing that’s going to get us a cure.”

Kevin Sinfield CBE on completing his fourth challenge to raise awareness and funds for MND inspired by his friend and former team-mate Rob Burrow CBE



Being signed up to an early access programme was part of the reason I was able to share my diagnosis with my daughter. It gives her hope there might be a cure in the future... she was able to see the positive despite my diagnosis.”

Eleanor Dalley, who has MND



“We are very pleased to be supporting the great work the MND Association does, especially since we lost our colleague Rachel to the disease. We look forward to further success in helping develop treatments and ultimately a cure”

Toyota (GB) President and Managing Director Augustin Martin



“I have met with my councillor regarding adopting the MND Charter and the Act to Adapt campaign to make sure people with MND lead a life with dignity they deserve”

Shahla Croxford, an MND campaigns volunteer whose husband died from MND

“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

“I believe that by sharing our stories and knowledge we can build a stronger and more supportive community for those affected by MND”



Susan Graham, whose sister Jaspal died from MND

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

Yvonne Johnson, who is living with MND



“I wanted to show people that you can still do something positive, even if you’re living with MND. I also wanted to help support my local branches and contribute towards MND research.”

Mark O'Brien, Guinness World Record breaker for the longest non-stop unaided open water swim by a person living with MND



The MND Association supported me and my family in a big way. We were able to get much-needed items”

Steve Wharton who received a Quality of Life grant



Whoever you are, you will gain from coming to the ALS/MND Symposium because you’ll meet incredible people and you’ll come out realising that there are a huge number of people who are pushing really, really hard to find the cure and treatments.”

Dr Rick Nelms, MND Patient Fellow who is living with MND



The Cost of Living Support grant made a huge difference as money is so tight these days. Without this help we would be further in debt”

Stephen Williams, who is living with MND

“The plan was to initially fund the post to ensure continued support for people living with MND while campaigning for funding to be reinstated. Fortunately, our efforts were rewarded when the Government reversed its decision and awarded permanent funding for the post.”

Don Connolly, Chair of the Jersey affiliation of the MND Association



“When you realise you’re running for someone who’s fighting a battle that most of us can’t even imagine, it puts everything into perspective. To be part of that, raising money for the MND Association will always be something I am immeasurably proud of.”

Gareth Birchley, top individual fundraiser at the 2023 London Marathon whose continuing fundraising efforts in support of The Broad Appeal are already funding two research projects in their entirety



The MND Association benefits advice service has been fantastic they give great advice and follow up a few weeks later.”

David Mangan who has MND



Thank you

Thank you to everyone who supported us during the year, especially:

Association patron **Rob Burrow CBE and his family** for their continued support throughout the year

Association patron **Kevin Sinfield CBE, his team and everyone who supported** his fourth MND challenge raising £550,000 for the MND Association

Our fantastic community of **25,000 fundraisers** who collectively raised £11,760,155

The **My Name's 5 Doddie Foundation** – for its continued generosity and partnership in our Care Grants Programme

The **Darby Rimmer MND Foundation** for its continued generosity and partnership in our Care Grants Programme

The **Netherby Trust** for its support of new Association visitors with a grant of £120,000 over three years

Stonegate for its continuing partnership, this year raising nearly £415,000

All our incredibly supportive **Think Tank partners**

The **Constance Travis Foundation** for its renewed pledge of £150,000 over three years

The **Barbara Naylor Charitable Trust** which is supporting a PhD research studentship over three years

Stand Against MND for the donation of £50,000 towards MND research

Our branches and groups which raised £3 million

The **Chloe Kipling Annual Giving Fund** for its generous gift

Toyota (GB) Plc for supporting our MND support grants through its charity partnership, raising over £183,000

The **Alan Davidson Foundation** for its continuing support throughout the year raising £150,000

The **Heaton-Ellis Trust** for its new grant to support research at King's College London

Garfield Weston Foundation for its support of the Pete Bellenger Memorial Rowing Challenge

The **Masonic Charitable Foundation** for supporting a PhD studentship

All our **trust, corporate and individual supporters** who made significant donations during the year.

If you would like to support us, please visit www.mndassociation.org contact us on **01604 611860** or email us at fundraising@mndassociation.org

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Front cover image: Mike who is living with MND, pictured with his wife Zoe.

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