

How your support in 2022 moved us closer to a world free from MND



12

16

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Welcome!

We are delighted to present our Impact Report for 2022, charting the progress and achievements made possible by our members, volunteers, supporters and staff.

Our ultimate vision of a world free from MND remains the same. But in 2022 our journey towards that goal changed.

The start of the year heralded the launch of our five ambitious Promises which now drive everything we do. They have given us a renewed focus to accelerate the search for new treatments and drive improvements in care and support for people with MND.

As an Association, we've promised, we won't rest until:

- 1. MND is treatable and ultimately curable
- 2. Everyone gets the care they need when they need it
- 3. Every day with MND counts
- 4. You are heard
- 5. No one faces MND alone

Throughout 2022, the money you donated and raised has enabled us to increase momentum, pushing forward groundbreaking research, improving care for people living with MND and contributing to campaigns which ensure our community's voice is heard - and listened to.

Together, we will not be beaten.



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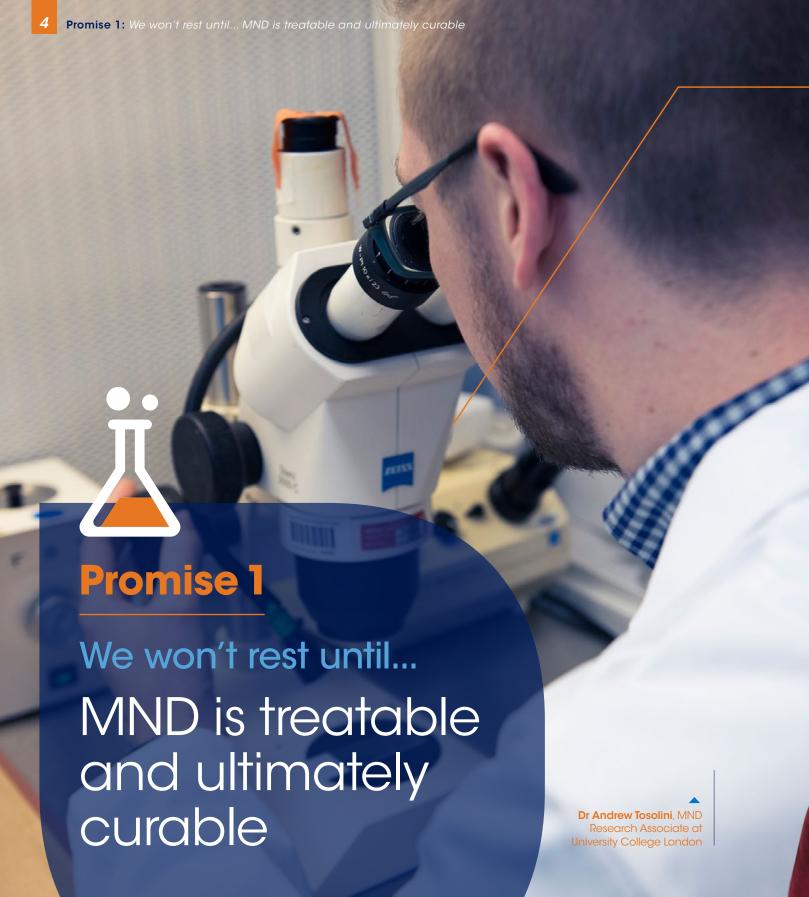
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Commonwealth Games gold medallist Sarah Davies with Helen one of our Regional Fundraisers at the Lift Me Up weightlifting event raising funds for the MND Association.





At the heart of ground-breaking research

We are proud to be the UK's biggest charitable funder of MND research, and a trusted partner on the global stage.

We continue to support cutting edge projects run by some of the best MND researchers in the world, which have brought us to the cusp of breakthroughs and treatments that will change lives.

We're securing the future of MND research by identifying the brightest young minds in the field to develop into the next generation of dedicated MND researchers. In July, we organised MND EnCouRage UK – the first in-person event of its kind aimed at inspiring researchers in the early stages of their careers to continue focusing on the disease. They met people with MND to hear first-hand why their work in laboratories and clinics is so important. And they were given the backing of our Royal Patron, HRH The Princess Royal who joined them for part of the day.

R

I've never liked the idea of being beaten by something and I've never liked the idea of giving in. That's why I said yes to being involved in several clinical trials with the hospital, and it's why I share my story to raise awareness of MND. I'm trying to make something positive out of my situation"

Mike Sumner, who is living with MND





MND researchers are no longer people who sit in a lab doing things that we don't understand, there is a human touch that didn't seem to be there before. When researchers come to conferences or focus days, they make it so easy to understand the incredibly complex work they're doing. I'm more hopeful than ever for treatment and a cure for MND."

Cris Hoskin, whose two sons died of MND



Our commitment to research is producing encouraging results. We provided crucial funding for the MIROCALS clinical trial - with support from the Jon Moulton Charitable Foundation and the Garfield Weston Foundation - which showed a statistically significant effect on survival.

The results of the MIROCALS clinical trial show encouraging signs of chinks in the armour of this disease as we continue with our research to develop effective treatments for MND."

Dr Brian Dickie, Director of Research Development

The trial investigated the use of interleukin-2 (IL-2) as a treatment for MND with results revealing the risk of death at 21 months decreased by more than 40% (for eight in ten of those who received the treatment).

Results were announced at our annual International Symposium on ALS/MND in December, which brought together the world's leading MND researchers to showcase latest developments – a total of 1,292 delegates from 44 different countries.

We are a step closer to more accurately measuring the progression of MND, thanks to Project AMBRoSIA, which we funded with the support of London City Swim Foundation and the Linbury Trust. Currently, neurologists use the ALSFRS-R scale which relies on self-assessments and assessments by healthcare professionals. The research study has shown measurement of neurofilament light (Nfl) chain in blood is a reliable, and objective, indicator of MND progression. If adopted in clinics, Nfl tests could help neurologists monitor progression more effectively. That, in turn, will lead to people with MND

receiving more personalised care.

Kick-starting new research

We continue to drive collaboration between research institutes and funders. In June, we contributed £1 million to a new £4.25 million grant to kick-start a collaborative MND research effort across six UK universities.

The funding was pooled through the UK-wide MND Collaborative Partnership formed to speed up progress and help research move towards the clinic and, ultimately, reach patients faster. The partnership team is working to find solutions to problems currently hindering MND research by improving laboratory drug testing practices, further developing the MND Register to gather more comprehensive information on the disease and supporting people to take part in clinical trials more easily.

It brings real hope to those of us living with MND to see our leading neuroscientists and charities coming together in this way."

David Setters,

who is

living

with

MND

MO

£2.4m

was invested in supporting clinical trials



£1m

was contributed to a

£4.25 million grant to kickstart a collaborative research
effort across six universities



£6.1m

was the value of **36**new research grants
awarded

Promise 2: We won't rest until... Everyone gets the care they need when they need it **Promise 2** We won't rest until... Everyone gets the care they need when they need it

Providing the care that's needed

MND is complex and people living with the disease experience it in different ways. That means each person requires specific support and care at different stages. And we've promised they will receive it.

That support, which research has shown improves quality and length of life, is most efficiently and effectively provided by a co-ordinated, multidisciplinary team of healthcare professionals. Last year, 3,972 people with MND benefited from just that at one of the 22 Association-funded Care Centres and Networks across England, Wales and Northern Ireland. Nigel Hazell (right) is one of those people.

Yet, we know not everyone receives the quality of care they need and are working to address gaps by highlighting unmet need, sharing best practice and creating partnerships for change.

We are also reviewing the NICE guideline on assessing and managing MND to identify gaps in current guidance so we can make recommendations to improve the care received by people with MND.

Leading MND researcher, Professor Ammar Al Chalabi (left) holds an MND multidisciplinary team meeting at King's College London We first met the MND
Care Centre team over
video call, including the
dietitian, speech and
language therapist,
nurse, and they're all
great. I feel valued
that several
people are
interested in
us and our
needs."

Nigel Hazell,

who is living with MND



We've launched our Access to
Multidisciplinary Care project that will see
the arrival of 14 community specialist roles
in specific geographical areas, bringing
care closer to home for people living with
MND. The specialists will co-ordinate care
through a multidisciplinary care team
working across targeted communities.

We've established new partnerships with the NHS in four priority areas and work is ongoing to create a further six in the first half of 2023.

The partnerships will create dedicated posts that will expand the availability of co-ordinated high quality multidisciplinary care in areas of greatest need.

New roles funded

New MND clinics opened by the Birmingham MND Care Centre for the West Midlands, thanks to the recruitment of a new MND Care Co-ordinator – Beth Pudjianto. The role has been funded by us with the help of many generous supporters. This brings additional resource to the team supporting people with MND and gives them the opportunity to do more.

The Care Centre team continues to work in partnership with hospice organisations to expand services and has established two new nurse-led clinics in Hereford and Stratford-upon-Avon.

Care shouldn't ever be a postcode lottery. One of the great things about my role is looking at what is working really well and implementing it elsewhere. We are bringing services together.

Beth Pudiianto,

MND Care Co-ordinator funded by the MND Association

Learning and sharing

Representatives from all 22 Care Centres and Networks came together on a day in June to focus on our commitment to ensure everyone gets the care they need when they need it. The spotlight was shone on current initiatives to improve access to multidisciplinary care and psychological support.

During the day specialist staff from Lancashire and South Cumbria, South Wales and Birmingham shared how they are using evidence to shape practice. They also discussed the current psychological care and support for people with MND and the implications for research and clinical practice.

Developing good care

A new part of our care offer is the MND Professionals' Community of Practice, a peer-led group of health and social care professionals encouraging and supporting the development of good care.

It offers professional development to health and social care professionals who can then offer enhanced MND care to people living with or affected by the disease.

£969,000

was committed to our 22 Care

<u>Centre and Network Programme</u>

1,000

training sessions given to health and social care professionals on communication aids for people with MND

957

health and social professionals were registered as members of The Community of Practice

HSPCs attended online training each month

256

members of The Community of Practice attended our information and knowledge exchange events

Making **EVELY day** count

We've promised to make every day count for people living with MND – and that means making sure they can live as well as possible.

Our NextGen Think Tank is harnessing the efforts of international technology giants including Rolls-Royce, Google and Microsoft to help people with MND use their voice for as long as possible – retaining their personality, independence and quality of life.

Last year we invested £79,276 in supporting people with MND to download their banked voice and use it via communication gids.

Our volunteer network of more than 300 Association visitors (AVs), also continues to provide an invaluable service to people with MND across England, Wales and Northern Ireland – offering one to one support, signposting and advice.

Ever

Eventually MND will take every part of me but I know now it can't take my voice. I've got that tucked away where MND can't reach."

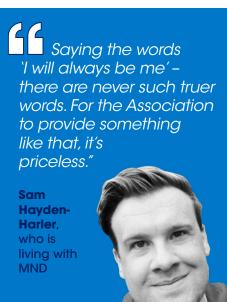
Sue Lodge (pictured with her husband) is living with MND and has banked her voice.

Michael Small who is living with MND, and his partner Mary. Michael was one of the first people to bank his voice using

the e-book I Will Always Be Me







We're guaranteeing access to new voice banking technology for people living with MND.

In February 2022, we launched *I Will Always Be Me* – a unique e-book which enables people with MND to bank their voice while reading the first-person story of an MND diagnosis aloud to loved ones, creating memories to cherish.

Thanks to our funding and further donations from Dell Technologies and Intel, it is free to use for anyone living with MND in England, Wales and Northern Ireland, and in Scotland, thanks to a partnership with MND Scotland.

Last year, more than 1,200 people registered to use the e-book - 569 people living with MND - as well as many others with conditions affecting speech. The combination of the book and technology have slashed the time it takes people to record their voice for future use from around three months in 2018 to just 30 minutes.

Sam Hayden-Harler, who is living with MND, was one of them. Sam lives with his husband, James, and son, nicknamed Little Man.

£818,470

in Support Grants was distributed to 873 people living with MND £362,270

in Quality of Life Grants was awarded to 907 people living with MND £53,995

was awarded across 218 Children and Young People Grants 10,000

calls taken by our MND Connect helpline



Influencing international companies

Our NextGen Think Tank continues to focus on its voice project to help people with MND retain the natural sound of their voice and spontaneity of speech.

The latest innovation was showcased at its October summit, hosted by BT. Google's Project Relate accessibility app, developed with the support of people with MND and our experts, helps people with MND communicate better by transcribing their speech. People with nonstandard speech can teach the app to understand their unique speech patterns and communicate.

It's already making a difference.

Yvonne Johnson, who is living with MND, helped Google develop the app.

With Project Relate's 'Repeat' feature, I feel better understood - not just by unfamiliar listeners but also my husband - it's the difference between a meaningful conversation and someone just nodding."

Yvonne Johnson

Here for you

Our Association visitors (AV) play a vital role, offering free, confidential emotional and practical support to people affected by MND either over the phone, via email or in-person.

We know that because you told us so.

As part of our AV Evaluation project to find out what difference the service makes and how we should develop it, we asked people with MND, our 323 Association visitors and our staff.

Eight in ten people with MND said they feel less isolated, thanks to the work of their AV.

Bereaved carer Lizzie Smith, whose husband John died of MND, found the service invaluable.

"Our AV Carmel was amazing and I'm still in touch with her now. Even if she didn't know something, she would do her damnedest to find out and point me in the right direction."

Last year we trained 78 new AVs with support from the Netherby Trust. More than 1,300 people are currently being supported by an AV.

We've also opened new avenues of emotional support for children and young people, and their loved ones, through a collaborative partnership with Barnardo's, Last year we helped 174 families through 549 one-to-one support sessions and cut the time youngsters have to wait for this kind of support from 18 months to just five days.





Hearing our VOICE

We've promised that people with and affected by MND will be heard. That means listening, raising our voice alongside theirs and amplifying their message.

By doing that, together we are driving change.

Awareness of MND and the Association has increased. In the 2022 Charity Brand Index we ranked number 77 for awareness, up 23 places since 2019 – in no small part thanks to the efforts of our patrons Kevin Sinfield OBE and Rob Burrow MBE.

In 2022 we were featured in dozens of newspapers, magazines, on radio stations and television.

Our team, along with a family affected by MND, helped shape the portrayal of MND on the small screen, working with the production team of primetime BBC1 drama *The Split*. David Mangan, who is living with MND, tuned in.

"I'd been on the internet searching my symptoms, and at the same time I was watching The Split, which featured an MND storyline, and I'd seen all the publicity with Rob Burrow, so

> there was a heightened awareness of MND in my own mind. Although it was a shock to be diagnosed, it wasn't unexpected."

David Mangan

The public really seem to know about MND now - we're seeing it everywhere. 20 years ago, when I started volunteering with the Association, people hadn't really heard of the condition."

Lesley Connor, volunteer

We've influenced decision-makers through our own campaigners, collaborating with other organisations and using our champions in parliaments in London, Cardiff and Belfast. In Westminster – members of the All-Party Parliamentary Group (APPG), currently chaired by Andrew Lewer MP, marked its 20th anniversary.

We remain incredibly grateful for the support of our patrons, **including our Royal Patron HRH The Princess Royal**, who continue to use their platforms to spread the MND message.





For an unprecedented ten consecutive days in November, BBC Breakfast followed Kevin Sinfield OBE's third epic challenge inspired by Rob Burrow MBE, his former Leeds Rhinos teammate and friend.

Ultra 7 in 7 saw Kev run seven ultra marathons in seven days during which his fundraising brought in an amazing £2,456,119 for the MND community including the Association Donations continued into 2023

Rob and his family were featured in a second documentary Rob Burrow: My Life With MND which itself sparked an invitation for Rob to become the first nonspeaking person to read a CBeebies Bedtime Story.

Having played an important role in the *United To End* MND campaign, the media continued to put pressure on the Government to deliver the £50 million pledged

for targeted MND research. At the end of the year, we welcomed an announcement by the Secretary of State for Health and Social Care about the distribution of the majority of the money to research institutes.





'Delighted to be present for passing of all stages of the Social Security (Special Rules for End of Life) Bill big thanks to @mndcampaigns @MarieCuriePA & campaigners everywhere



'Six months' scrapped

In 2022, four years of campaigning culminated in His Majesty The King granting Royal Assent to the Social Security (Special Rules for End of Life) Bill, as one of his first legislative acts as monarch.

The rubber stamp scrapped the six-month rule in all four UK nations, a change we had strived hard for alongside Marie Curie. People with MND, and other

terminal illnesses, no longer need to prove they have less than six months to live before being able to use fast-track access to benefits.

Campaign progress

In October, our campaigners attended the Senedd and were pleased to secure support from 20 Members for our Welsh Homes for MND campaign, focusing on the housing adaptation process for people living with MND.

Similarly, in England, our Act to Adapt campaign has scored successes. For example, in Sefton in Merseyside, the council has pledged to introduce a fasttrack process for people with MND and remove financial assessments for Disabilities Facilities Grants under £5,000 for those living with the disease.

We took the fight for unpaid carers to the top in two nations.

In November, we attended the launch event of Carers Northern Ireland's new report *The State* of Caring 2022: A snapshot of unpaid caring in Northern Ireland, giving us the chance to meet with Stormont Members of the Legislative Assembly.

A month later we were at Westminster, launching our Support MND Carers campaign

to review Carer's Assessments following the publication of our report into the impact caring has on the loved ones of people with MND. ITV's Good Morning Britain presenter and our patron, Charlotte Hawkins, publicly supported the campaign.



2.3million



people visited our website - 1.8m were unique visitors



49million+

impressions on social media with more than 1.8m engagements



₹ c.72,000

pieces of information were downloaded or sent to people affected by MND



5.376 plays of our MND Matters oodcast



34,500

copies of our quarterly magazine Thumb Print were distributed. It was viewed online almost 9,500 times across the year



Being here for everyone

MND can affect anyone. And no one should face it alone. That means us reaching out to every community and removing any barriers there may be to accessing the support, care or services which can make a difference.

We've been developing engagement projects in several areas of England and Wales, firstly to help us understand more about the needs of people affected by MND in specific faith and ethnic communities. This insight has helped us build connections, raise awareness and offer people what they need to reach out to us and benefit from our support.

The learnings from each project help shape subsequent ones taking us nearer to our goal of being attuned to the needs of communities throughout England, Wales and Northern Ireland..

We are learning from our partnerships

with other organisations – for instance, the Association is now a Stonewall Diversity Champion and a Disability Confident Employer.

When someone whose first language isn't English is diagnosed with MND, half the time they don't understand what's happening to them. I can speak Hindu, Punjabi and Urdu. When I speak to people in their first language, I see them open up more quickly because they understand what I am talking about."

> **Devinder Kalkat** long-term supporter of the Association in the West Midlands, whose husband died from MND in 2002

Steve and Byron celebrate with friends and family on their wedding day in Chester



Involving people with **MND** in shaping our work

Our new Collaboration Community, launched in 2022, is growing fast and allows people affected by MND to have a say and get involved in shaping our plans and our work. We create better solutions by involving our community in our work.

Richard Collyer, who is living with MND, worked as a project manager and has used his years of experience to support an Association care project.

Our range of network groups bring people with MND, volunteers and staff together to offer mutual support and share experiences. We also ask them to hold us to account, to make sure we're getting it right for everyone.

Ahmed Abdeldayem, who chairs the LGBTQIA+ network group, said: "The network is open to people with and affected by MND, volunteers and staff. It's been focused on increasing awareness and understanding of issues facing the community and ensuring these are taken into account in everything we do as an Association."

David Whalley, our Area Support Co-ordinator for the North, was instrumental in helping set up

our Hidden Disabilities and Conditions Forum. He says:

"The Forum is a safe space where people can be themselves, share issues and we can talk to see if there is anything the Association can do to help."

Furthermore, a report by the Welsh Government showed that for many Welsh speakers,

being able to access information and services in Welsh made a significant positive difference - improving their overall experience and wellbeing.

We listened - and as a result, launched our Welsh Language Scheme, developing information about MND and the support on offer in Welsh.



Richard Collver

74,997

posts were added to our online forum by 2,348 members



11,154

people were registered as members of the **Association** by the end of the year

£2.3m

was contributed to our central funds in addition to local initiatives by **our** 90 Association branches and groups



30 million thank yous!

For the first time ever, in 2022 our income topped £30 million.

That's an incredible total made possible by the generosity of so many people.

Of particular note are the public efforts of our patrons Kevin Sinfield OBE and Rob Burrow MBE, whose own endeavours have inspired so many others to get involved and raise funds. We have also benefitted from so many generous donations including the highest total amount ever received from people who have chosen to leave us a gift in their will.

It is now our responsibility to ensure we invest this money wisely, to make the biggest difference for people affected by MND.

£17.6m

was raised and donated by our incredible fundraisers, supporters, donors, corporate partners and funders with a further £2.3 million raised by our branches and groups. We are hugely grateful for your commitment and continued support.

£8.9m

was donated in 2022 in the form of legacy gifts which continue to make a massive difference to the work we do. We are hugely grateful to the people who choose to remember the work of the Association in their Wills.

Sources of Income

Fundraising - £17.6 million (58%)

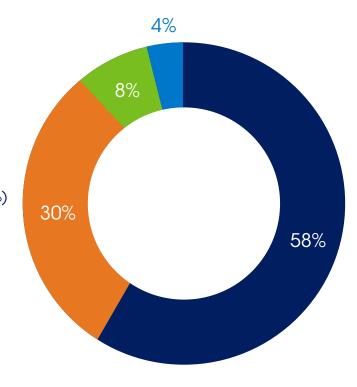
Legacies - **£8.9 million** (30%)

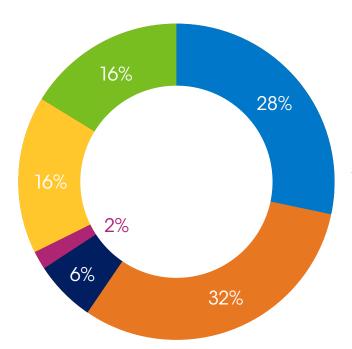
Branches and groups - £2.3 million (8%)

Earned income - £1.2 million (4%)

Total income for 2022:

£30 million





How we spent the money raised

Care and support - £6.4 million (28%)

Research - **£7.2 million** (32%)

Campaigning - £1.4 million (6%)

Volunteer development - £0.5 million (2%)

Fundraising - £3.7 million (16%)

Support costs - £3.7 million (16%)

Total expenditure for 2022:

£22.9 million

You are making a difference. **Together** we are more powerful and **together**, we will beat MND.



The **Betty Messenger Charitable Foundation** for its donation of £2 million

The Barbara Naylor
Charitable Trust for
supporting our PhD
Studentship programme

Our community of fundraisers – a record 9,607 people raised over £6.6 million

Everyone who ran the **London Marathon** in 2022 raising a record £597,000

The **Childwick Trust** for supporting our research programme

The **Stephen Hawking Foundation** and the
Hawking family for their
continued support

The **Linbury Trust** for its support of Project AMBRoSIA

The Masonic Charitable Foundation for fully funding a PhD Studentship at University College London The **Netherby Trust** for supporting our Association visitor training programme

The Constance Travis
Foundation for its grant of
£50,000 towards MND care
services

The Catherine Cirket

Discretionary Trust for the
gift of £20,000 towards

Association visitor support
and care

The **Inman Charity** for supporting MND research

My Name'5 Doddie Foundation for its continued partnership and commitment to our care grants programme

The Wolfson Foundation for a pledge of £75,000 towards our communication aids and wheelchair support programme.

The **Heaton-Ellis Trust** for its long-term support of MND research

Guernsey MND Branch for supporting our research programme

The William Brake
Foundation for its ongoing
donations to our research

The Freshfield Foundation for its long-term commitment to MND research

The Alan Davidson
Foundation and Hayes
Davidson for their
continued support of
our care and support
programme

Bruce Wake Charitable Trust for supporting MND research

Knight Frank for its generous and continuing support

Rolls-Royce, Dell, Intel and Google - for working alongside us on the NextGen Think Tank The Jones 1986
Charitable Trust for supporting the Nottingham MND Care Centre

Basil Samuel Charitable Trust for donating £30,000 towards MND care

The Cinquefoil Trust for supporting our equipment loan service and MND support grants

Berry Bros & Rudd for its continued support

The **Darby Rimmer MND Foundation** for supporting our care grants programme

David Setters for his ongoing fundraising and the organisers of the David Setters Trophy cricket tournament for the £31,000 raised

The Street family and friends for completing their latest challenge of climbing 47 peaks in five days raising more than £50.000

Julie Cook and family for organising the London Comedy Lunch and for their continuing support

Novuna for raising £60,000 at a fundraising event

Challenging MND for a £100,000 gift supporting our quality of life and emergency grants programme

St George's Day Club for its gift of £25k following its annual lunch

Good Racing Co Ltd, Beep Burrow Racing Club and Jedd O'Keefe Racing, Caddick Group, Pontefract Academies Trust, Elite Pro Sports, Arc Inspirations

The Ultra 7in7 team, Leeds Rhinos, Leeds Rhinos Foundation, Elite Pro Sports, Arc Inspirations, RAM films for supporting Kevin Sinfield OBE's Ultra 7in7 Challenge. All those **supporters** who wish to keep their generous donations anonymous

Our patrons and ambassadors for their continued support

We are grateful for the support of companies which have chosen us as their charity partner. In 2022, we were chosen as **Stonegate Group's** charity partner and the partnership has raised over £230,000. Last year also saw the continuation of our three-year partnership with **Toyota (GB) Plc** with the aim of raising up to £300,000 for our support grants programme.



2022 has been **another extraordinary year** for the MND Association...





and that's all down to you!



So, we turn our attention to 2023. With solid foundations in place and an extraordinary year of fundraising behind us, we have the opportunity to use the surplus funds generated in 2022 to invest in new projects. While our core work will continue, the drive to deliver our five ambitious Promises will step up a gear, thanks to the incredible support we've had.

We will seek out the research projects which are most likely to accelerate the development of effective treatments and invest in them. We will work to extend the care and support available to everyone with and affected by MND. We will shout louder about MND to ensure the voice of the MND community is heard by those who can make a difference.

And we hope you will continue to work alongside us, and the MND community, to strive for even more this year.







A message from our Chief Executive

As you can see in this report, 2022 was a very special year for the MND Association. It was the year we **raised over £30 million for the first time,** the year our research portfolio topped £20 million and the year we launched our Promises to the MND community.

That sets the bar high for 2023. We must embrace the opportunity to build on this work; to drive forward the research that will deliver effective treatments; to collaborate to ensure people have the coordinated care and support they need; to campaign for a better quality of life; to inspire more people to fundraise for us; and to amplify the voices of people affected by this brutal disease.

As the new Chief Executive, it's my responsibility to lead the team to do all of that. I feel hugely privileged to be in this position and also very excited. Already I can

see the passion and determination there is in the MND community. You – our members, supporters, volunteers and campaigners - are making a difference every day. Today we are nearer to our vision of a world free from MND than we've ever been.

And we will get there. Together.

Tanya Curry

Chief Executive MND Association



If you would like to support us, please visit www.mndassociation.org contact us on 01604611860 or email us at fundraising@mndassociation.org

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