

Imagine a world where support for people living with motor neurone disease (MND) is within easy reach for everyone; a world where technology helps people with MND live their lives to the fullest; a world where MND is a disease that can be quickly diagnosed and effectively treated.

Imagine a world where MND is no longer a mystery and when you say the words 'motor neurone disease' everyone you speak to knows and understands.

Imagine a world where being told you have MND doesn't mean it's the end.

This is the world our community is fighting for.

A world where MND doesn't win.

Sam with her husband Casey, who was diagnosed with MND aged just 19



hanks to your generosity and continued support we've been able to do even more to support people living with MND and their families.

Throughout 2021, the money you have donated and raised has been hard at work, improving care and support for people living with MND and driving forward ground-breaking research.

With the Government committing £50 million into drug development over five years and with clinical research and clinical trials taking place in MND research labs and clinics across the UK, there is increasing optimism among the scientific community that meaningful treatments for MND could soon be within reach.

Thanks to you, our Association is stronger than ever, with fresh ideas, bold ambitions and a dynamic, inclusive approach to the work we do.

Together, we will not be beaten.

Together we will beat MND.

We're the driving force behind a new era in MND research

n explosion of knowledge over the past ten years has turned MND into one of the fastest growing areas of neurological disease research - and the MND Association is right at the heart of it.

As the biggest charitable funder of MND research in the United Kingdom, and a trusted partner on the global stage, the Association's continued investment over many years has laid solid foundations for progress and encouraged collaboration between today's researchers around the world.

In 2021, the Association's research commitments encompassed 83 research grants at a collective value of £15.1 million. Our influence, coupled with our continued investment, has encouraged others within the sector to invest funding, including leading medical research charity, LifeArc, which has named motor neurone disease as one of the 'translational challenges' they will focus their efforts on.

This year alone, with the incredible support of our community behind us, we were able to allocate an additional £2 million for innovative translational research, which bridges the gap between academic discovery and the development of new therapies. Exciting research into gene therapy – which has the potential to revolutionise the treatment of MND – is already under way. Clinical trials have led to new potential approaches to treat people living with



1,118 researchers and clinicians from 44 countries joined the Association's Symposium on ALS/MND in December

mutations in genes such as C9orf72, SOD1 and FUS, and, if successful, may also have the potential to stop the disease developing in those who may be at risk.

In December, the Association brought the world's leading MND experts together for the 32nd International Symposium on ALS/MND, which, due to the pandemic, was held online for the second year. The four-day event showcased the latest developments





in MND research. Over the years, the Symposium has seen the growth of many new ideas, paving the way for ground-breaking new initiatives including Project MinE, which has been responsible for identifying the majority of the genes associated with MND to date.

As we look ahead, we are witnessing the dawning of a new era in MND research.

The knowledge of leading MND experts from around the world, together with on-going investment from the Association, the generosity of our supporters, our partners in the charity sector and growing interest from the pharmaceutical industry and the Government, mean we have never been closer to developing effective new treatments - and ultimately, a cure for MND.

£4.3 million of new funding invested in

'A catalyst which will transform MND research'

The time it takes to develop new treatments for MND could be reduced by years, thanks to the promise of £50 million of Government investment into leading MND research institutes.

In November, the Government announced it would be investing £50 million in targeted MND research over the next five years in response to the hugely successful United To End MND campaign. The campaign was led by our amazing campaigners, including David Setters, Lee Millard and many others who are living with MND, and supported by the MND Association and our partners at MND Scotland and the My Name'5 Doddie Foundation.

Speaking on BBC Breakfast following news of the announcement, leading MND expert, Professor Chris McDermott from the Sheffield Institute for Translational Neuroscience (SITraN) explained that the £50 million investment would make clinical trials quicker and more efficient and give people living with MND the chance to take part much more easily.

News of the Government's pledge, which came on the back of unprecedented coverage in the national media, was a huge moment for the whole MND community.

> "The UK has some of the world's top MND researchers. A boost to MND research funding like this will make a big difference to what we can do and help accelerate the search for a cure. We are very grateful to all the people who campaigned so hard to make it happen."

Professor Ammar Al-Chalabi, neurologist and MND research specialist, King's College London

We're making it easier for people with MND to access the support they need

e know that being diagnosed with MND is devastating, often leaving people confused about where to turn for support or what to do next.

The MND Association is determined that people living with MND have the help they need, and, with your continued support, we've taken an innovative approach to the information we offer. We're using the lessons learned from the pandemic to make it easier, quicker, and more convenient for people living with MND to get hold of the information and support they need when they need it.

We're committed to making sure that people living with MND can access co-ordinated multi-disciplinary care, something which is shown to improve quality of life and life expectancy. During 2021, our 22 care centres and networks across England, Wales and Northern Ireland supported 3,883 people living with MND.

Our practical support in the form of our support grants has continued, thanks to the overwhelming generosity of our supporters and partners. In 2021, we distributed £1.1 million of support grants to 1,682 people living with MND. We distributed 182 Emergency Support Grants worth £45,000 to offer a helping hand to people living with MND, struggling with additional living costs as a direct result of the pandemic. And children and young people living in homes affected by MND received 160 grants worth almost £38,000, helping to pay for everything from horse-riding sessions to driving lessons.

Our podcast, *MND Matters*, which launched in 2021, ensures that people affected by MND can listen to information and support at the click of a button. The monthly episodes, recorded in-house by a small team of staff and featuring people living with MND and their families, cover everything from conversations about continuing to work when you have been diagnosed with MND, to helpful updates on voice banking and support with bereavement.

Throughout the year, our amazing volunteers and supporters have brought the MND community closer together, holding many support, and branch and group meetings in-person and online, making it easier for people living with MND to connect with, and get involved in, the work of the Association.



73,477

pieces of information downloaded and sent to people living with MND and their families

£69,028



of funding was distributed to 90 people living with MND to help with wheelchair equipment

"I am normally a very active person and although I am at the early stages of MND, my day is only tolerable if I can do things, a bit of woodwork or gardening. The 'rising chair' accessory [for my wheelchair], which this grant paid for, will allow me to access my tools and work bench so I can still be creative for as long as possible." Anonymous



"I find I switch off when I try to read long pieces of information nowadays. However, I've started listening to the MND Matters podcast, I've listened to every episode so far and that's a good way to get information as I can sit and listen to them quite easily."

lan, living with MND

Bringing support closer to home

Our network of 339 Association visitors provides important one-to-one support to people living with MND and their families.

Anne Hobson was diagnosed with MND in January 2021 and was quickly put in touch with an Association visitor, Heidi.

Anne said: "Reeling from the shock of having been diagnosed with MND I did not want to engage with the folder packed with information that I was given by medical staff.



"My husband Tony immediately joined our local branch, which, we had been assured, would be a great source of comfort at such a stressful time. He was asked if we would want one of the Association's volunteer visitors to contact us. We said, 'Yes,' and we got a call from Heidi. In that first call she and I just clicked. I cannot remember exactly what we talked about in that first conversation, but of course, tears were shed. An hour went by quickly and Heidi asked whether I would like her to phone again. I said, 'Yes, please,' feeling already that here was someone from outside the family circle to whom I could talk very easily and frankly about my emotions.

"I hope that Heidi will be able to stay with me during this difficult journey. For now, I am just grateful for all the Association has done and continues to do for me and especially thankful that I have Heidi in my life."





£1.19

million of eligible benefits was claimed through our Welfare Benefits Advice Service

We're making sure people living with MND are heard

> eople living with MND have continued to make the Headlines in 2021, leading to significant prime-time coverage on television and radio and countless column inches being written in the national press.

During 2021, the Sunday Express newspaper, which has an average readership of 2.7 million each week, got behind the United To End MND campaign. Every Sunday, for 20 weeks, they featured the story of people living with, and affected by MND, and were instrumental in helping to secure the £50 million for MND research institutes, which has now been promised by the Government. Our thanks to the newspaper's former



The #United2EndMND campaign reaches Westminster

editor Mick Booker and his team for their support and for helping to give people with MND a voice

Right across England, Wales and Northern Ireland, people living with MND and their families have shown tremendous courage in sharing their own, deeply personal experiences of MND bringing the reality of MND to life for millions in local newspapers, on local radio, in podcasts such as the Association's MND Matters and online. Our Speakers' Network has been set up to give people living with, and affected by MND, a chance to explain - in their own words – just how devastating MND can be. The network empowers people living with

> MND to share their stories and allows the Association to raise awareness of MND at a local level.

While it's impossible to place a monetary value on the coverage we have received this year, we do know that, thanks to the support of our community, millions more people now know about MND and the work of the Association, leading to a marked increase in donations and people coming forward to help us. It is this extraordinary support and awareness that allows us to go even further to help people living with MND and their families.

"I'm a talker, my way of dealing with things is to talk them out. I do like telling my story to raise awareness of MND. I cope by doing it too."

Cris, who has lost six members of her family including her two sons - to an inherited form of MND



Kevin arriving at the Leeds Rhinos **Emerald Headingley Stadium at** the end of his epic journey

Millions tune in to watch Kevin's epic challenge

It was Association patron Kevin Sinfield OBE who captured our hearts once again at the end of 2021, when he ran the equivalent of four marathons in 24 hours as part of his epic Extra Mile Challenge.

Kevin organised the challenge, which saw him run the 101 miles from Leicester to Leeds. to honour his best friend and former rugby league team-mate Rob Burrow MBE, who was diagnosed with MND in December 2019.

Alongside his own dedicated team, and with Association supporters following him every step of the way, Kevin ran his way into the nation's hearts – raising more than £2.1 million – with half being donated to support the Association's work.

Kevin and Rob's story of enduring friendship featured extensively on BBC Breakfast, with 2.3 million people tuning in to see Kevin cross the finishing line at Leeds Rhinos Headingley Stadium on the morning of 23 November.

As well as a substantial increase in donations, the coverage led to offers of help, encouraged new donors and funders to support us and prompted many fundraisers to take on challenges of their own, in some cases for the very first time.

We would like to thank Rob and his family, Kevin

Sinfield and his wider team, Leeds Rhinos, Leicester Tigers and the many hundreds of people who were inspired to support the Extra Mile Challenge. We would also like to thank the Burrow Seven Racing Club, Pro Elite Sports, Arc Inspirations and many other individuals, schools and teams for their continued support.

fighting motor

neurone

disease

We are also incredibly grateful to BBC *Breakfast* editor Richard Frediani, and his team, for their support on and off-screen, and for continuing to follow Kevin and Rob's story.

"We wanted to provide some" hope. So many families have been devastated by MND, including Rob's. While he is willing to fight like he is, then we will too."

Kevin Sinfield OBE



We're one community united behind the same goal

ur Association is made up of thousands of different voices, from diverse backgrounds and communities right across England, Wales and Northern Ireland.

We have different skills and experiences and our contribution to the work of the Association is as unique as we are – but when we come together as one, we're a thriving community which is impossible to ignore.

In 2021, our campaigners came together to make decision-makers across the three nations sit up and take notice, helping to make life better for people living with MND and their families.

After three years of tireless campaigning by the MND Association and our partners at Marie Curie, the process of claiming benefits is set to be made easier for people living with MND thanks to the success of the *Scrap 6 Months* campaign. In July, the Association was delighted to learn that the six-month rule will be axed when it comes to accessing the Special Rules for Terminal Illness fast-track, extending it to everyone whose life expectancy is a year or less.

Right across the Association, we continue to encourage our members, and particularly those who are living with MND, to get more closely involved in the work we do, helping to steer our projects, get involved in our campaigns, volunteer for us and help us shape our plans for the future.

As part of our on-going commitment to diversity, equity and inclusion, we've created two new network groups for people living with and affected by MND, our volunteers and staff from the LGBTQIA+ and BAME communities, helping our community to feel welcome, safe, supported and empowered to help us make a difference.



"My MND has progressed enormously. We're exhausted, angry and have no energy for anything but the basics of daily living. If it wasn't for the NHS, the MND Association and our local hospice, we would be high and dry."

Nigel, who is living with MND, and has had to wait 11 months for a grant assessment from his local council to adapt his home

75,000 people supported the Scrap 6 Months campaign



We're pushing for a fairer system for everyone

The Association is committed to making sure everybody who is living with MND can live in a safe and accessible home.

In early 2021, the Association launched its *Welsh Homes for MND* campaign, calling on the Senedd to make it easier for people living with MND to get the housing adaptations they need.

In March, following a Senedd debate, the Welsh Government announced that it would drop means-testing on small and medium disabled facilities grants. Since then, our campaigners have continued to meet with members of the Senedd to raise awareness of MND and push for faster progress.

In England, the Association's Act to Adapt campaign has also gained momentum.

A local campaign on The Wirral resulted in the local council introducing a fast-track grant scheme for terminally ill people, while talks continue with councils across the country, encouraging them to change their policies.

In November, more than 400 supporters contacted their local councillors, inviting them to attend an online event to learn more about *Act to Adapt*. Those who attended learnt more about the importance of the campaign and heard from a number of Campaigns Volunteers, many of them affected by MND, about why the system is in urgent need of improvement.

In the coming months, we'll be ensuring that housing adaptations continue to be a key priority for consideration by MPs.



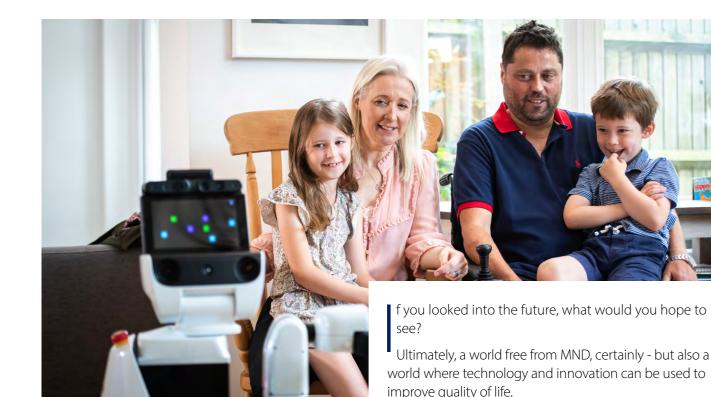
Access to home adaptations for people with Motor Neurone Disease



SCRAP6M[®]NTHS



We're embracing new technology to help us improve lives



While it sounds like something from science fiction, it's quickly becoming science fact thanks to the work of the MND Association's Next Generation Technology Think Tank. We're proudly working alongside technology giants communication aids were

including Intel, Dell, Google and Rolls-Royce and our charity partner, car giant Toyota GB, harnessing their vast expertise to tackle the problems that people living with MND face and the ways that technology might be used in the future to ensure people living with the disease can continue to live their lives to the fullest.

One of the innovations supported by the Think Tank is a Human Support Robot (HSR) which is being developed by Toyota GB. The robot can assist people living with MND with everyday tasks such as bringing a carton of orange juice from the fridge or passing objects such as a TV remote control.

The prototype, which is in development and not currently available, was first used in the UK by Anthony Walsh, who was diagnosed with MND in May 2021. As the disease progressed, he experienced significant weakness in both legs and used a wheelchair to move around his home, something he found increasingly frustrating.

He explained: "Not being able to walk for the last month has been very hard to cope with. I've lost my mobility and I have to be dependent on others, which is not the sort of person I was. We're just getting the first taste of what the future might hold and what technology is out there. I think there could be a place where this robot could be there to help people in different ways with their day-to-day life. It gives you back a little bit of your independence, albeit you're still relying on something else."

Sadly, Anthony died in October 2021, but his family have kindly given their permission for his story to be shared to help raise awareness of MND and the work being done to support those living with this devastating disease.

loaned out to people living

with MND during 2021

54

Finding new ways to improve the support we offer

While the Think Tank looks to the future, the Association is using technology to extend the range of support we can offer to people living with MND right now.

With 80% of people affected by MND experiencing some difficulty with their speech, the work we do to improve access to communication aids is critical.

The Association loans equipment such as iPads, iPhones, Lightwriters and other devices and also provides access to apps.



We help people to bank their voice as soon as possible after diagnosis and are working with our partners to develop new technology to help improve the process. Free training is also offered to professionals who are working with people living with MND. In 2021 more than 1,500 people attended the monthly online training events with 99% of those taking part rating the training as excellent or good.



We're also using technology to make it easier for people living with MND and their families to access the information they need. Using our Care information finder, visitors to our website can find a package of information, including links to publications, animations or web pages, related to their search term, simply by clicking a button.



"After my diagnosis, my partner and I left the hospital like zombies. I then had a meeting a month later with the nurse consultant from the MND Care *Centre. It covered everything. She gave* me practical support and mentioned voice banking. She showed me an MND Association information sheet and urged me to do it as soon as possible, so I made it a priority. I used SpeakUnique and saw a message on the website saying I could apply for funding from the MND Association, so I applied. It was quick, in a matter of hours I had an email back saying they had funded it." Jennie, who is living with MND

How we spent the money raised

£6.48

raised for every pound spent directly on fundraising in 2021. When legacy income and costs are included, this rises to £9.16

£18.2 million

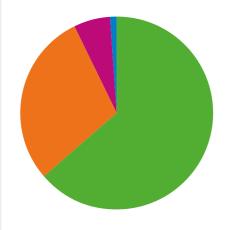
was raised and donated by our incredible fundraisers, supporters and funders and a further £1.8 million was raised by our branches and groups. We are tremendously grateful for your commitment and continued support.

£8.5 million

was donated in 2021 in the form of legacy gifts which continue to make such a huge difference to the work we do. We are enormously grateful to the people who choose to remember the work of the Association in their Wills.

These numbers are provisional and are subject to final approval by the Association's Board of Trustees. For a full breakdown of our annual accounts please refer to our *Annual Report* which will be available in June 2022.

Total Income for 2021: £28.9M



Sources of income

Central fundraising **£18.2M (63%)**

Legacies

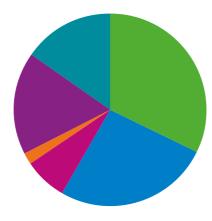
£8.5M (30%)

Branches and groups

£1.8M (6%)

Earned income £0.4M (1%)

Total Costs for 2021: £18.1M



How we spent the money raised

Care and support (inc. by branches and groups) **£5.9M (33%)**

Research

£4.6M (26%)

Campaigning and raising awareness **£1.4M (7%)**

Volunteer development **£0.4M (2%)**

Fundraising £3.1M (17%)

Support costs £2.7M (15%)

"Their kindness lives on in the work we do daily"

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he MND Association is extremely grateful for the generous donations we receive each year from people who choose to remember us in their Wills.

In 2021, we received £8.5 million from gifts in legacies, money that has helped us to make a significant difference to the lives of people who are living with MND.

In East Sussex, a generous legacy has helped to fund the work of two MND care co-ordinators, who help to put people living with MND and their families in touch with the right support.

One of the MND care co-ordinators, Katherine Smith said: "We are incredibly grateful to the person who left a legacy to fund our posts. When we think about it and reflect upon our work, it is humbling and touching to think that, even at their most vulnerable, someone took the time and effort to improve the lives of people living with MND. This person's kindness lives on in the work we do daily."

In 2021, 128 people wrote their Will using one of our Free Wills schemes which ensure our supporters and people living with MND have their affairs in order and gives peace of mind that their loved ones are protected.



MND Care Co-ordinators Katherine Smith and Vicky Lester



"I left a gift in my Will to the MND Association to give hope to other people with MND and to find a cure, so they don't go through what I am."

Cath, who is living with MND, pictured with her sons

Thanks to you 2021 has been an exceptional year

eightened awareness of MND and an increase in donations from our amazing supporters – our incredible fundraisers, branches and groups, donors, funders and members - meant the Association ended 2021 with a significant surplus to invest in our services. In such uncertain times, we realise this is an extremely fortunate position to be in, and we are incredibly grateful to our community for continuing to support us.

We know people living with MND do not have time to wait and neither do we. That's why your generous donations are already being put to work, helping us bring forward vital projects which will improve the lives of people living with MND today, while paving the way for even greater progress in the future.

Among the key areas which will benefit from this investment is research into MND. We are determined to harness the extraordinary momentum we have seen in MND research in recent years by investing an additional £5 million in translational research on top of the £500,000 invested in 2021 and a further £1.5 million that is already budgeted in 2022. This additional money will be spent on speeding up the clinical trial process and make it easier for people living with MND to get involved in clinical research through improved use of technology. Thanks to the very positive financial position, additional funds will also be spent on helping to improve care for people living with MND and their families, including driving forward our technology, partnerships and working with the NHS to improve services.

To learn more about our commitment to the MND community and our priorities, or to get involved, visit www.mndassociation.org/ MNDPromises.





We couldn't do it without you

very day, the support you give to the MND
Association is making a difference to people living with MND and their families.

Thanks to you, we're widening the support we can offer, we're demanding better standards of care, and we're paving the way for a brighter tomorrow with investment in technology and ground-breaking research.

Together we are powerful and together, we will beat MND.



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We would like to thank:

Rob Burrow and his family, Kevin Sinfield and his wider team, Leeds Rhinos, Leicester Tigers and the many hundreds of people who were inspired to support the Extra Mile Challenge raising more than £1million.

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

The Linbury Trust which donated £50,000, making a total of £200,000 gifted to MND research in memory of prima ballerina, Annette Page.

The Netherby Trust which generously supported the training of new Association visitors.

The James Tudor Foundation.

Stuart Bates and Charlotte Nichols who created the Spennylympics and personally completed all 102 Olympic events, raising more than £155,540.



The Constance Travis Foundation for their grant of £50,000 to MND care services and for pledging £150,000 over a three-year period.

The Barbara Naylor Charitable Trust which pledged to fully fund a PhD research studentship over three years.

The Betty Messenger Charitable Foundation and a family trust that wishes to remain anonymous for their committed support of the MND Register.



Q

Club Triumph for raising more than £100,000 for the Association.

Our charity partner Toyota (GB) Plc for supporting our wheelchair services.

Our partners at Intel, Dell, Google and Rolls-Royce for working alongside us on the Next Generation Think Tank.

The Mark Armitage Charitable Trust for supporting our research and care programmes.

Challenging MND, which made a significant grant in support of our care grants programme including Covid Emergency Grants.

The Alan Davidson Foundation for its grant following the HD5k Virtual Run in 2021 and ongoing support for our care programme.

Fortlands, for its generous support in 2021.

The Ian Karten Charitable Trust for supporting our equipment Ioan bank.

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



The Stephen Hawking Foundation and the Hawking family for their continued friendship and involvement over many decades.

The Darby Rimmer MND Foundation for its continued generosity and partnership in our care grants programme.

Former footballer Len Johnrose, who is living with MND, for leading the #IceFoot92 challenge which generated income and fantastic awareness on national TV.

The speakers and contributors who took part in our Insights events during lockdown, including Zoe Ball, Sir Chris Bonington, Cherie Blair CBE QC, Daniel Franklin, Christian Fraser, Lucy Hawking, Charlotte Hawkins, Sue Hayward, Dr Sheila Kanani MBE, Ore Oduba, Sarah Outen MBE and Davy Zyw.

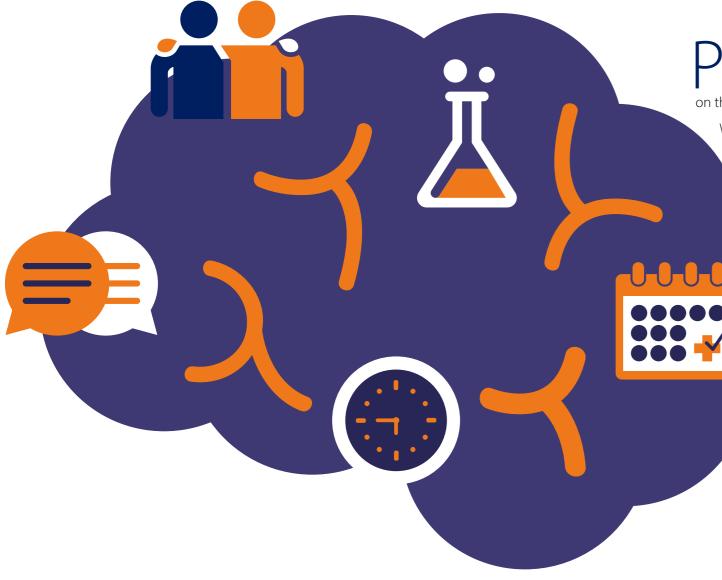
Our patron, Eddie Redmayne OBE, for donating £50,000 following his voiceover of Marks & Spencer's Christmas 2020 advert.



Our Royal Patron, patrons, ambassadors and all our celebrity supporters for their time and commitment.



2022 and beyond: our promises to you



eople living with MND, their families and carers are – and always will be – at the very heart of everything we do, and this year we intend to build on that enduring commitment.

With awareness of MND higher than it's ever been and the support of our extraordinary community behind us, the MND Association's vision for a world free from MND has never been closer.

> We are determined to beat MND once and for all – and we've started 2022 by making five promises to the MND community which will help us make it happen.

• Every day with MND counts

You are heard

With your help, we won't rest until:

MND is treatable and ultimately curable

• Everyone gets the care they need when they need it

No one faces MND alone

These are bold promises – and ones that we don't take lightly. They have been made following discussions with people living with MND and our wider community. With your support we will keep them.

Thanks to the kindness and generosity of our supporters, we have been able to invest more funds into the key projects which underpin our promises, and you can read more about the progress we have made already on page 16.

While our current financial position will go a long way to accelerating our long-term plans, we will still need to raise at least £20 million a year to ensure we can deliver the vital services people living with MND rely on and fund further progress in MND research.

For people living with MND and their families, your donations, and the support you offer, has never been more important.

A message from our Chief Executive



Sally at Headingley stadium, the home of Leeds Rhinos rugby league team, thanking our supporters Glenn Milne and Chris Smith who volunteered their services to drive a motorhome as a support vehicle for Kevin Sinfield during his amazing 101 mile run in November 2021 For our Association – and the wider MND community – the past year has been extraordinary.

From the success of the *United To End MND* campaign, to the heroics and generosity of all our supporters and all the amazing coverage and column inches you have helped to create, 2021 has been the year that has seen us achieve more than we ever thought possible.

Of course, none of it would have happened without the unwavering support of our community – members, volunteers, supporters and campaigners – and we are so grateful for everything you have done, and continue to do, to further our work.

But as we look ahead to the future, what happens next has never been more important.

There can be no doubt that, together, we have turned a corner in the fight against MND. With the promise of effective treatments for MND now emerging, we have never been better placed to beat MND once and for all.

Every decision we take from now on will be crucial, every single moment counts and every pound you donate will be more powerful than ever.

People living with MND and their families are relying on us to act upon the promises we have made, and, with the support of our community behind us, **we will not** *let them down*.

Sally high





Any photos have been provided to us by the supporters concerned in the activity.

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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Tel: 01604 250505 Email: enquiries@mndassociation.org

www.mndassociation.org









Front cover image: The Matthews family who raised £5,500 for the MND Association by taking part in Mission 5000, to support Chris (seated centrally) who is living with MND.

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