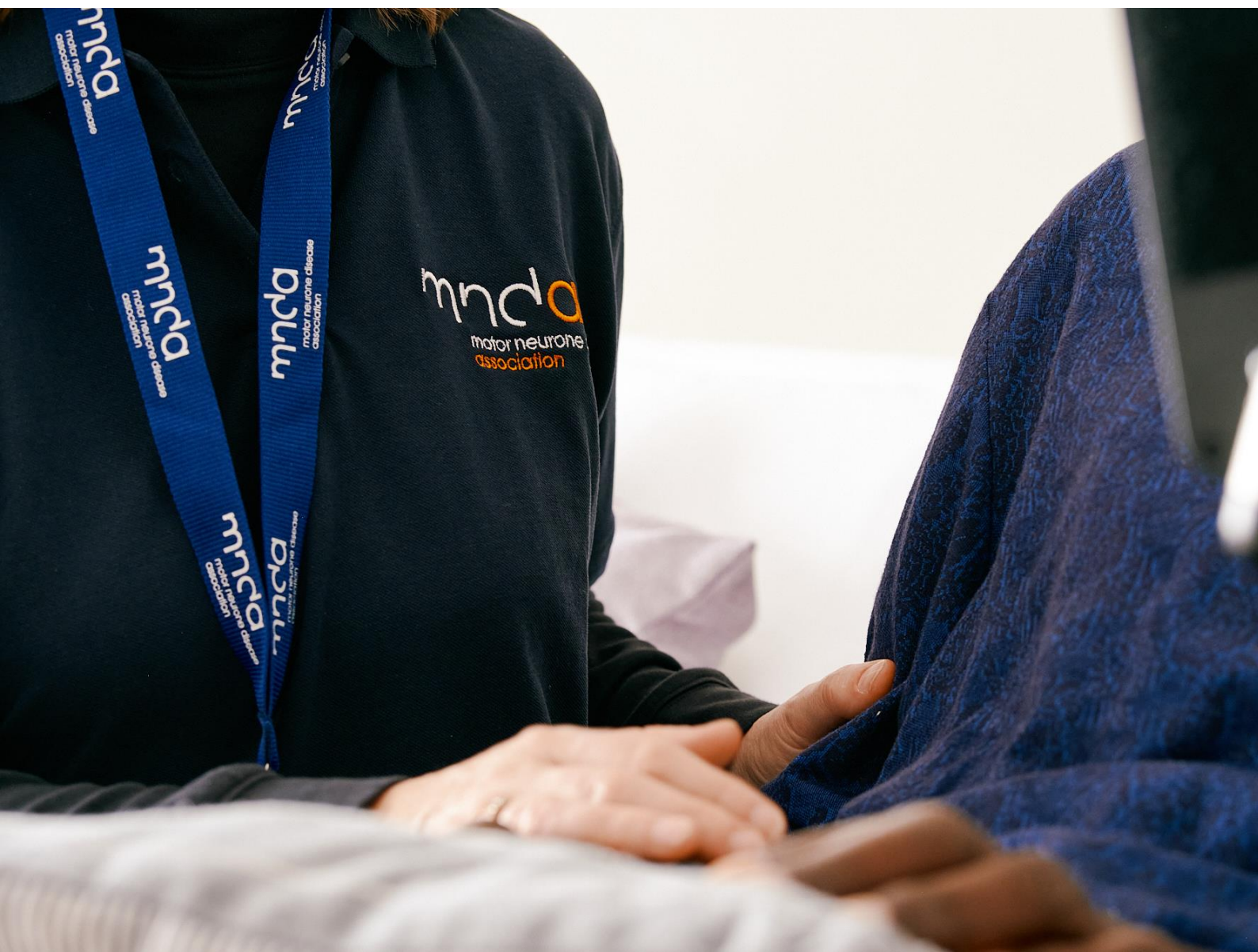


Candidate pack

Lead Research Nurse

Working towards a world free from MND



About MND and the work of the Association

Motor neurone disease (MND) is a fatal, rapidly progressing neurological condition affecting more than 5,000 adults in the UK at any one time. The disease causes messages from nerves (motor neurones) in the brain and spinal cord that control movement to gradually stop reaching the muscles, leading them to weaken, stiffen and waste.

The result is that people become locked in a failing body, unable to move, talk and eventually breathe. Some may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia. MND does not usually affect senses such as sight, hearing and touch.

MND kills a third of people within a year and more than half within two years of diagnosis. It affects people from all backgrounds and a person's lifetime risk of developing MND around 1 in 300. Today six people will be diagnosed and six will die from MND. There is no cure.

The MND Association focuses on funding research, improving access to care and campaigning for people living with or affected by MND in England, Wales and Northern Ireland. We have over 11,000 members forming a powerful network that provides information and support for people with MND, their families and carers. We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure. We campaign and raise awareness so the needs of people with MND are recognised and addressed by wider society.

People with MND, their families and carers are at the heart of everything we do



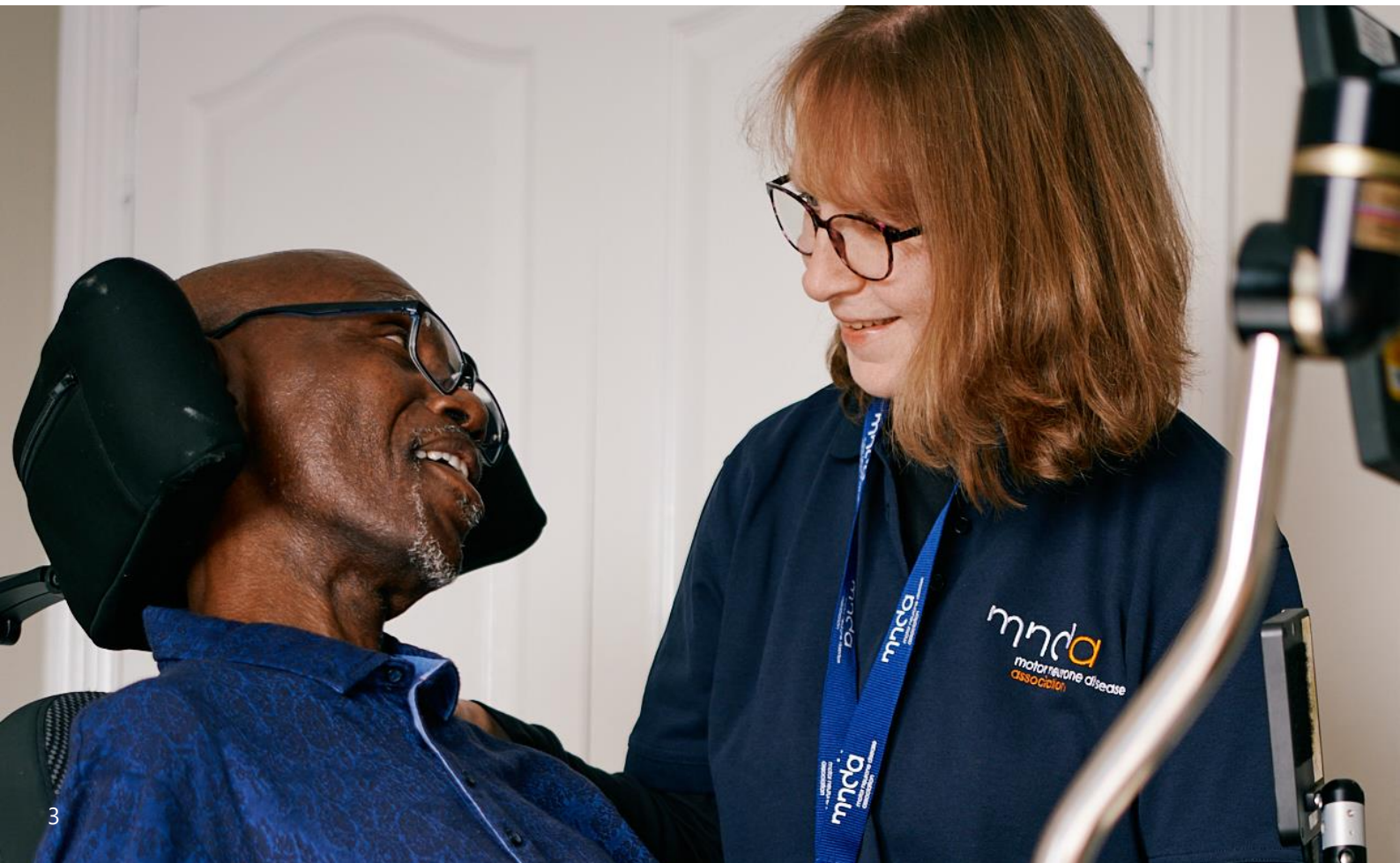
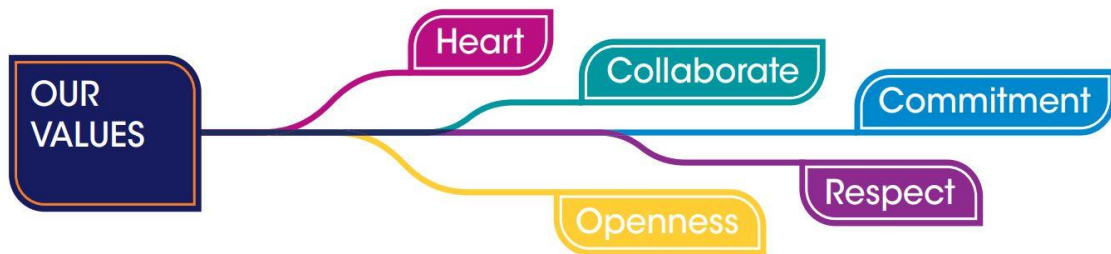
Our vision and values

Our vision

A world free from MND.

Our Values

- People with MND, their families and carers are at the **heart** of everything we do.
- We **collaborate**, and value everyone's contribution.
- We achieve excellence through personal **commitment** and ongoing improvement.
- We **respect** and respond to people's diverse needs, backgrounds and views.
- We achieve our aims through building **open** and transparent relationships.



Our Promises

To harness the hope within our community to speed up progress towards a world free from MND, the MND Association has committed to five Promises. Our Promises give us focus to work faster and fight harder to strive for better – together with our community. Simply put, they drive everything we do.

Promise 1 We will not rest until: MND is treatable and ultimately curable

We are seeking new collaborative drug discovery and development projects, helping to fund and facilitate the research that is taking us ever closer to uncovering the causes of MND, effective treatments and ultimately a cure.

Promise 2 We will not rest until: Everyone gets the care they need when they need it

Co-ordinated multi-disciplinary care is the very best way to ensure a person with MND has access to all the healthcare professionals they need, at the right time. Our 22 care networks across the country provide this. But not everyone with MND has access to the same level of support. That must change.

Promise 3 We will not rest until: Every day with MND counts

For people with MND, technology can help life be the best it can be. We are working with tech giants from around the world to find solutions to real-life problems.

Promise 4 We will not rest until: You are heard

If we shout louder and to the right people, things will change. If we all join together we can't be ignored.

Promise 5 We will not rest until: No one faces MND alone

We will work to break down barriers that prevent people with and affected by MND from accessing the help and support they need.



Job Description

Job Title: Lead Research Nurse
Reports to: Director of Services and Partnerships

Job purpose

- Support the creation of the MND Association Research Nurse Network to achieve the MND Association's ambition that everyone diagnosed with MND has the support and opportunity to take part in clinical research.
- Develop and lead the research nurse programme within the MND Association with accountability for all aspects of the national research nurse programme, including strategic direction, recruitment, management and leadership, education, and training.
- Facilitate the provision of high-quality care for patients in clinical trials in accordance with international regulatory frameworks.
- Collaborate with the MND Association, Services and Partnership directorate including Education & Professional Development, Heads of Regional Services & Partnership. There will be a particularly strong connection with the Director of Research and the broader work of research participation.
- Work with the research nurses to publicise and promote the work of the MND Association amongst patients, professionals, and the public.
- Provide organisation wide expertise on issues relating to patient care and all phases of clinical research and act as a spokesperson to a variety of audiences, including media (traditional and social), health professionals, supporters, and the general public.

Role Of the MND Association Research Nurse Network

Over the next 5 years the MND Association is providing investment to create an MND Association Research Nurse Network to enable more people living with MND to take part in research trials.

MND Association Research Nurses will be based at specialist MND Care Centres and Networks across England, Wales and Northern Ireland.

The creation of the MND Association Research Nurse Network will support our ambition that everyone diagnosed with MND has the support and opportunity to take part in clinical research.

The MND Association believes access to clinical research should be equitable and part of the holistic care available to everyone diagnosed with MND.

MND Association Research Nurses will help people with MND navigate the research trial process, providing information about current MND research trials, identifying trials people are eligible for, explaining what is involved, and supporting people with their application and ongoing involvement in trials.

Main responsibilities

Management & Leadership:

- Develop and implement an MND Association Research Nurse Network and strategy to support the delivery of the MND Association's operational and research strategy.
- Manage and support the research nurse network providing close links with the Care Centre Network.
- Contribute to local appraisals and reviews as appropriate.
- Collate data to produce annual reports and inform business planning.
- Prioritise research nurse activities ensuring maximum impact and value for the MND Association.
- Ongoing evaluation of research nurse cohort, ensuring appropriate use of resources to deliver the strategic goals of MND Association. This includes monitoring the agreed financial contract and agreements.
- Coordinate regular team meetings and support visits, ensuring the development of a cohesive network.
- Represent MND research nursing and nurses at national and international level where required.

Education & Training:

- Develop a recognised network of research nurses with specific skills, expertise, and objectives.
- Apply knowledge of the ethical principles for clinical research.
- Possess and apply specialist knowledge of the roles of the National Research Ethics Service (NRES), Governance Arrangements for Research Ethics Committees (GAfREC), and Research Ethics Committees (RECs).
- Provide advice and support to other members of the multidisciplinary team with an in-depth knowledge of ICH GCP and R&D and REC registration and approval in relation to project development, implementation, completion, and distribution.
- Ensure compliance with ICH GCP guidelines.
- Coordinate the induction of new research nurses.
- Collaborate with the Education & Professional Education department to create training materials to support the induction of research nurses and support continuing professional development.
- Ensure good communication and consistent messages by holding regular meetings of the research nurses.
- Maintain an up-to-date knowledge of current advances in MND clinical trials and distribute this knowledge internally and externally.
- Prepare and deliver presentations relating to clinical research and the MND Association's support of this.

Main responsibilities

Partnerships:

- Establish and maintain excellent relationships with the Care & Research Centres & Networks.
- Establish national strategic relationships at a senior level with key policy leaders in health and research. UK MND Research Institute and the UK MND Clinical Studies group.
- Work with local Trusts to ensure the research nurses can allocate sufficient time for MND Association activities and are clearly identified as an MND Association nurse.
- Strengthen the identity of the MND Association nurses within national research organisations ensuring the brand is promoted.
- Collaborate with internal departments to engage patients and people affected by MND research at a local and national level.
- Undertake any other task relevant to the job purpose and ensure that all functions performed reflect the Associations mission and core values.

Essential criteria

- Registered Nurse with substantive experience in clinical research
- Comprehensive knowledge of UK clinical trial regulations.
- Experience as a research nurse, supporting clinical research.
- Experience of leading a team of nurses.
- Evidence of service development.
- Evidence of implementing change.
- Leadership skills capable of establishing purpose and direction within complex organisational structures.
- Ability to translate and communicate complex information to a variety of audiences.
- Advanced decision-making skills.
- Ability to work in partnership at all levels internally and externally.
- Excellent communication, influencing and negotiating skills.
- Experience in neurodegeneration or life-limiting illness studies is preferrable.

Salary

£60,000 per annum on a full-time permanent basis.

Location: Home-based

This is a home-based role with travel requirements to Care Centres & Networks across England, Wales and Northern Ireland as required (Flexibility to attend the office on occasion may be required to meet business needs.)

Pension

The option of the Auto Enrolment Scheme where the employee and employer both contribute 4% of your monthly salary, calculated after tax and national insurance (NI) have been deducted or an Enhanced Salary Sacrifice Scheme where the employee contributes a minimum of 5% and the Association contribute 8.1%, calculated before tax and NI are deducted.

Annual leave

28 days of annual leave, which increases by one day for each full calendar year worked, up to a maximum of 33, in addition to the recognised bank holidays.

Additional Benefits

- UK Healthcare: We provide level 1 cover, which reimburses healthcare costs including dentist, optician, health screening, specialist consultation and much more. Discover more [here](#).
- You and your household have 24/7 access to GP appointments, prescriptions and advise, all at no extra cost. Discover more about GP24 [here](#).
- Access to a confidential counselling helpline. Support for your health and wellbeing, including challenges related to family, work, finances and health.
- My Healthy Advantage: Access to the wellbeing app providing interactive tools to support your health and wellbeing.
- Salary sacrifice schemes include:
 - Save money and spread the cost of a new bike whilst reducing your carbon footprint.
 - Buy and sell up to 5 days annual leave.
- Life assurance: additional financial protection for your loved ones, ensuring piece of mind and a secure future.
- BenefitHub: Save money on your everyday shopping with access to 100s of high street discounted vouchers and offers, including cash back plans.
- Opportunities for training and personal development.

How to apply

Please submit a CV and supporting statement via our [website](#). This ensures your application is processed correctly and we have all the required information.

Your supporting statement should be no longer than one side of A4 and demonstrate how you meet the following areas of the role:

- Expert knowledge of nursing practice, UK clinical trial regulations, and multi-disciplinary teamwork.
- Develop a recognised network of research nurses with specific skills, expertise, and objectives.
- Demonstrate experience of working within complex organisations.

Where experience is asked for, please give one example showing what you did and what it achieved. Where we require evidence of ability, please explain either how you would approach that particular competence or give an example to support your suitability.

Please note, adverts may be closed before the deadline if sufficient applications are received. To avoid disappointment please apply early.

All applications will receive a response once shortlisting has been completed.

Inclusive recruitment

We are committed to providing people with disabilities an opportunity to compete fairly for jobs.

- We guarantee interviews for disabled applicants that meet the requirements of the role as part of our commitment to the Disability Confident Scheme.
- We can provide reasonable adjustments throughout the recruitment process.
- We communicate with applicants in a way that works best for them to ensure a positive and supportive candidate experience.

Alternative application process

To support an inclusive application process, we are open to receiving alternative applications from candidates who may find it difficult to complete our online form. If you would like to apply via video or audio file, please send your recorded application - ensuring you cover the supporting statement aspect - to HRRecruitment@mndassociation.org

Privacy Policy:

The information provided to the MND Association when applying for a vacancy will be treated in full accordance with the General Data Protection Regulation (GDPR).

The MND Association is committed to protecting your personal information and being transparent about what information we hold, whether you are a donor, volunteer, shopper, campaigner or a person living with or affected by MND.

For more information, visit [Privacy Policy | MND Association](#)

Right to work:

If you are successful in securing a role at the MND, you will be asked to produce your valid right to work documentation as part of our pre-employment checks. To find out more please visit our [website](#).

DBS checks:

Depending on the nature of your role you may be required to complete a criminal records check with the Disclosure and Barring Service (DBS).

Animal testing statement:

Research using animals has led to a greater understanding of MND. Because of the complexity of MND, at the moment animal models are still one of the most powerful tools used to help us understand, prevent and one day cure MND. Many of the achievements that stem from research funded by the MND Association, and by other organisations worldwide, would not have been possible without animal research. Even so, a great deal of our research is carried out without involving animals.

Any decision to use animals in research is never taken lightly. We understand that not everyone agrees with animal research. For more information, visit [Animal research | MND Association](#)

Looking out for our people

The wellbeing of our staff is very important to us, and that's why we've developed a wellbeing offer and programme of activities. These include:

- Mindfulness sessions
- Wellbeing sessions
- Menopause support group
- Parent and carer support group for children who are neurodivergent
- Less visible disabilities and conditions forum
- Mental Health First Aiders who provide support and signpost you to further information.

Learning and development opportunities

We understand the importance and benefits of continual learning. To facilitate your professional and personal growth, we provide a:

- comprehensive induction programme
- range of courses available on our Learning Management System - *Learning Lab*
- job shadowing policy, enabling you to strengthen your knowledge in other areas
- chance to study for an apprenticeship alongside your role.



Our commitment to inclusion

Motor neurone disease doesn't discriminate, and neither do we.

We are determined to become fully inclusive by continuing to embrace diversity, remaining committed to equity and ensuring that our products and services are fully accessible. In this way, we can ensure that **all** people living with and affected by MND get the best possible care and support they deserve.

We offer a variety of network groups and forums that are open to everyone, including our staff, volunteers, people living with and affected by MND, as well as Association members. These groups provide peer-to-peer support, raise awareness, and hold the Association accountable.

We are a Stonewall Diversity Champion, have recently been awarded Disability Confident-Employer status, and are members of the Communications Access Scheme.



Take a look at the [inclusion pages](#) on our website to learn more about our inclusion strategy, see how far we've come and where we are headed.



Where we work

Our central office is situated at Francis Crick House in Northampton, Moulton Park. It's a bright and modern space with a variety of flexible working spaces, meeting rooms, and communal areas.

We also have an office space in London, which is used predominately by our External Affairs Team. Some of our staff are based regionally and work from home.



Francis Crick House

Motor Neurone Disease Association

Francis Crick House,
6 Summerhouse Road Moulton Park,
Northampton NN3 6BJ
Tel: 01604 250505

MND Association

FORA
180 Borough High St,
London,
SE1 1LB



Francis Crick House



Our history

On 6 October 1979, three independent regional groups set up by people affected by MND came together for the first time as the MND Association. Professor Stephen Hawking accepted an invitation to be the Patients' Patron and remained a figurehead of the Association until his death in 2018.

Within a year, we had funded our first full time research fellow, based at Charing Cross Hospital's neurological department, and just two years later, in 1982, 40 specialists attended the Association's inaugural research conference.

Today, the Association funds the coordination of life-changing care for people living with MND and wide-ranging support for families and carers. We invest millions of pounds every year in the global research effort to discover the causes, potential new treatments and ultimately a cure for MND.

Visit our [website](#) to learn more about motor neurone disease and the important work we're doing at the Association.





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