

Debate Pack

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By Elizabeth Rough,

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e-petition debate on research into motor neurone disease

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1

Background

An e-petition ([564582](#)) on increasing funding for urgent research into motor neurone disease calls on the Government to “significantly increase targeted research funding for motor neurone disease (MND)”. It adds that a “new investment of £50m over 5 years could kickstart a pioneering MND Research Institute”.

The petition had received 110,700 signatures when it closed on 6 July 2021. The Government published a response to the petition in April 2021, emphasising that it was “working on ways to significantly boost further research into the disease”, while also highlighting where existing funding had enabled research to take place.

The petition will be debated in Westminster Hall on 12 July 2021 and will be opened by Martyn Day.

2

Motor neurone disease (MND)

Motor neurone diseases are thought to affect approximately 5000 adults in the UK, with about 1,100 people diagnosed each year.¹ They are a group of uncommon, progressive neurological conditions affecting the motor neurones (nerves) in the brain and spinal cord that control “skeletal muscle activity such as walking, breathing, speaking, and swallowing”.² There are several different types of MNDs, though all cause muscle weakness and worsen over time.

Symptoms and prognosis vary depending on the type of MND. The National Institute for Health and Care Excellence (NICE) states that “most people die within 2–3 years of developing symptoms, but 25% are alive at 5 years and 10% at 10 years”.³ In 2019/20 there were 4,458 hospital episodes in England where motor neuron disease was the primary diagnosis and 7,856 where it was listed as one of the secondary diagnoses (total episodes: 12,314).⁴

Early symptoms can include:

- weakness in your ankle or leg – you might trip, or find it harder to climb stairs
- slurred speech, which may develop into difficulty swallowing some foods
- a weak grip – you might drop things, or find it hard to open jars or do up buttons
- muscle cramps and twitches
- weight loss – your arms or leg muscles may have become thinner over time
- difficulty stopping yourself from crying or laughing in inappropriate situations.⁵

An overview of the different types of MND is provided in Box 1.

¹ Motor Neurone Disease Association, [What is MND?](#), June 2021; NICE, [Quality standards and indicators Briefing paper: Motor neurone disease](#), November 2015, p3

² National Institute of Neurological Disorders and Stroke (United States), [Motor Neuron Diseases Fact Sheet](#), August 2019

³ NICE, [Quality standards and indicators Briefing paper: Motor neurone disease](#), November 2015, p3

⁴ NHS Digital, [Hospital Admitted Patient Care Activity 2019-20](#), September 2020

⁵ NHS, [Motor neurone disease](#), 18 January 2021

1 Types of MNDs

“Amyotrophic lateral sclerosis (ALS): is the most common form of MND, with weakness and wasting in the limbs, muscle stiffness and cramps. Someone may notice they are tripping when walking or dropping things. Life expectancy is usually two to five years from the onset of symptoms.

Bulbar onset MND or Progressive bulbar palsy (PBP): affects a smaller number of people than typical ALS, and mainly affects the muscles of the face, throat and tongue. Early symptoms may include slurring of speech or difficulty swallowing. Life expectancy is between six months and three years from onset of symptoms.

Progressive muscular atrophy (PMA): affects only a small proportion of people. Early symptoms may show as weakness or clumsiness of the hands. Life expectancy is usually more than five years.

Primary lateral sclerosis (PLS): is a rare form of MND, causing mainly weakness and stiffness that usually begins in the lower limbs, although many people experience additional problems with their speech and various other symptoms. PLS is usually not life-shortening, as it progresses very slowly. It may take some time to confirm a definite diagnosis of PLS because slow progression in ALS may look similar at first.

Kennedy’s disease (also known as spinal bulbar muscular atrophy or SBMA): is not a type of MND but has similar symptoms. It is a rare condition affecting the motor neurones, with increasing weakness and wasting of the muscles. Unlike MND, Kennedy’s disease also causes hormonal changes. Due to their similarities, MND and Kennedy’s disease are sometimes confused at diagnosis. Most people with Kennedy’s disease live an average life span”.

Source: Motor Neurone Disease Association, [Are there different types of MND?](#), June 2021

The [NHS](#) notes that MND mainly affects people in their 60s and 70s, though it can affect adults of any age. Some MNDs are inherited; NHS Inform (Scotland) estimates that in about “5% of cases there’s a family history of either motor neurone disease or a related condition called [frontotemporal dementia](#)”.⁶ In the majority of cases, however, it is not known what causes motor neurones to stop working properly and degenerate. In non-inherited MNDs, it is thought that “environmental, toxic, viral, and/or genetic factors may play a role in the development of the disease”.⁷ At present, there is no cure for MNDs, though

⁶ NHS Inform, [Motor neurone disease \(MND\)](#), April 2021

⁷ National Institute of Neurological Disorders and Stroke (United States), [Motor Neuron Diseases Fact Sheet](#), August 2019

there are treatments that aim to manage symptoms and improve quality of life.

3

Research funding for motor neurone disease

The MND Association states that there has been a “massive upsurge in [MND] international research output in the last decade”⁸ and describes it as one of the “fastest moving sectors in UK health and biomedical research”.⁹ MND Scotland, for example, reported that there were over 2000 research studies published in 2015 on MND/ALS, compared to just over 500 in the year 2000 (based on PubMed entries).¹⁰ There is also optimism that increased research outputs will translate into new discoveries and, ultimately, treatments.¹¹

3.1

Sources of funding

In its [Response](#) to the e-petition, the Department of Health and Social Care explained that “Government funding for MND research comes via the National Institute for Health Research [NIHR] and UK Research and Innovation [UKRI]” but added that it was “not usual practice to ring-fence funding for particular topics or conditions”:

The NIHR and UKRI welcome funding applications for research into any aspect of human health, including MND. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money, and scientific quality.

Research funding also comes from the charity sector. The MND Association, for example, has a grants portfolio of approximately £14.6 million (as of 31 December 2020), which consists 85 grants.¹² It is estimated that the UK public donated over £7m as part of the “Ice Bucket Challenge” in the summer of 2014 and that \$100 million was raised world-wide through the challenge for MND/ALS research projects.¹³

Biotech and pharmaceutical companies have supported research into MNDs. The NIHR, for example, reported last year on trials for a new drug targeting

⁸ MND Association et al, [UK MND Research Institute](#), January 2021, p2;

⁹ MND Association et al, [Accelerating research for a treatment for motor neurone disease \(MND\)](#), November 2020, p5

¹⁰ MND Scotland, [Research Strategy 2017-2020](#), not dated

¹¹ Hopkins Medicine, [An answer to ALS?](#), Winter 2016

¹² MND Association, [Research we fund](#), not dated. Research grants and fellowships are also provided by other charities, such as MND Scotland, see [Research We Fund \(mndscotland.org.uk\)](#) and My Name’s 5 Daddie Foundation, see [Research | My Name’s 5 Daddie Foundation \(myname5doddie.co.uk\)](#)

¹³ MND Association et al, [Accelerating research for a treatment for motor neurone disease \(MND\)](#), November 2020, p4; [Remember the ice bucket challenge? It just funded an ALS breakthrough](#), The Guardian, 27 July 2016

the genetic cause of a rare form of motor neurone disease that had been supported by the NIHR as well as the biotechnology company Biogen Inc.¹⁴

3.2

Recent government funding for MND research

Data provided in response to Parliamentary Questions (PQs) indicates that the Government has spent the following on MND research through the NIHR and UKRI:

UK Research and Innovation (UKRI)

In 2019/20, UK Research and Innovation (UKRI), through the Medical Research Council (MRC), spent around £13.4 million on Motor Neurone Disease (MND) research. This included research which aims to increase our understanding of the causes and genetic mechanisms of MND and Amyotrophic Lateral Sclerosis (ALS) a form of MND. Over 5 years (2015/16 - 2019/20) MRC expenditure relevant to MND and ALS totalled £45 million.

In addition, UKRI, through the Biotechnology and Biological Sciences Research Council, supports a diverse portfolio of neuroscience research and innovation totalling around £30 million per annum. This work may underpin MND research by furthering current understanding of the structure and function of the nervous system; cell biology and genetics; mental processes including learning and memory.¹⁵

National Institute for Health Research (NIHR)

The Department of Health and Social Care has spent over £10 million on MND research over the past five years through the National Institute for Health Research (NIHR). In 2019/20 alone, the NIHR invested £2.7 million in MND research through NIHR research programmes and the NIHR Clinical Research Network.¹⁶

Additionally, the NIHR research infrastructure supported 73 research studies and trials on MND in 2018-19.¹⁷

The response to the June 2021 PQ also emphasises that the Government is:

strongly committed to supporting research into dementia and neurodegeneration, including motor neurone disease (MND). We are

¹⁴ NIHR, [New treatment for motor neurone disease shows promise in early trials](#), 13 July 2020

¹⁵ [PQ 22203](#) [on Motor Neurone Disease: Research], 30 June 2021

¹⁶ [PQ 22203](#) [on Motor Neurone Disease: Research], 30 June 2021

¹⁷ [PQ 126801](#) [Motor Neurone Disease: Research], 14 December 2020. Further information on historical spend can be found in [PQ 206942](#) [on Motor Neurone Disease], 3 September 2014

currently working on ways to significantly boost further research on dementia and neurodegeneration.¹⁸

3.3 Calls for further research funding

The [e-petition](#) specifically calls on the Government to invest £50 million over 5 years on a “pioneering MND Research Institute” on the grounds that it would “lead to better, faster and more definitive research outcomes and hope for those with MND”. The MND Association is campaigning alongside the My Name’s5 Doddie Foundation and MND Scotland for the Government to invest in a virtual MND Research Institute which, it states, would allow the Institute to “leverage inward investment from industry for every new drug in the pipeline”.¹⁹ The aims of the proposed Institute are:

- Create a drug discovery and development programme.
- Deliver a sustainable UK MND trials platform for rapid and efficient clinical trials.
- Develop a clinical research programme to ensure that as much as possible is being gained from each trial.²⁰

Detailed proposals for the Institute can also be found in:

- MND Association et al, [UK MND Research Institute](#), January 2021

¹⁸ [PQ 22203](#) [on Motor Neurone Disease: Research], 30 June 2021

¹⁹ MND Association et al, [UK MND Research Institute](#), January 2021, p2

²⁰ MND Association et al, [UK MND Research Institute](#), January 2021, p3-4; [Minutes](#) of the APPG on Motor Neurone Disease, 25 February 2021

4

PQs

[Motor Neurone Disease](#)

Asked by: McCarthy, Kerry

To ask the Secretary of State for Health and Social Care, what discussions he has had with the Chancellor of the Exchequer on the future funding of motor neurone disease (a) research and (b) treatment ahead of the 2021 Spending Review.

Answering member: Helen Whately | Department: Department of Health and Social Care

There have been no specific discussions. However, we are currently working on ways to significantly boost further research on dementia and neurodegeneration at all stages. The Department funds research on health and social care through the National Institute for Health Research (NIHR). The NIHR welcomes funding applications for research into any aspect of human health, including motor neurone disease (MND). Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.

NHS England and NHS Improvement commission the specialised care and treatment that patients with MND may receive from the specialised neurological treatment centres across England. Funding decisions for these are made in line with local priorities and in the context of the interim funding regime in place during the pandemic.

HC Deb 05 July 2021 | PQ 24129

[Motor Neurone Disease: Research](#)

Asked by: Carden, Dan

To ask the Secretary of State for Business, Energy and Industrial Strategy, what steps his Department is taking to accelerate research into motor neurone disease.

Answering member: Amanda Solloway | Department: Department for Business, Energy and Industrial Strategy

The Government is strongly committed to supporting research into dementia and neurodegeneration, including motor neurone disease (MND). We are

currently working on ways to significantly boost further research on dementia and neurodegeneration.

In 2019/20, UK Research and Innovation (UKRI), through the Medical Research Council (MRC), spent around £13.4 million on Motor Neurone Disease (MND) research. This included research which aims to increase our understanding of the causes and genetic mechanisms of MND and Amyotrophic Lateral Sclerosis (ALS) a form of MND. Over 5 years (2015/16 - 2019/20) MRC expenditure relevant to MND and ALS totalled £45 million.

In addition, UKRI, through the Biotechnology and Biological Sciences Research Council, supports a diverse portfolio of neuroscience research and innovation totalling around £30 million per annum. This work may underpin MND research by furthering current understanding of the structure and function of the nervous system; cell biology and genetics; mental processes including learning and memory and neuro. Additionally, the Department of Health and Social Care has spent over £10 million on MND research over the past five years through the National Institute for Health Research (NIHR). In 2019/20 alone, the NIHR invested £2.7 million in MND research through NIHR research programmes and the NIHR Clinical Research Network.

HC Deb 30 June 2021 | PQ 22203

[Motor Neurone Disease](#)

Asked by: McCarthy, Kerry

To ask the Secretary of State for Health and Social Care, whether he plans to increase funding for motor neurone disease research and treatment over the next five years.

Answering member: Edward Argar | Department: Department of Health and Social Care

The Department funds research on health and social care through the National Institute for Health Research (NIHR). It is not usual practice to ring-fence funding for particular topics or conditions. The NIHR welcomes funding applications for research into any aspect of human health, including motor neurone disease (MND). Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money, and scientific quality.

NHS England and NHS Improvement commission the specialised care and treatment which patients with MND may receive from the specialised neurological treatment centres across England. Funding decisions for these are made in line with local priorities and in the context of the interim funding regime in place during the pandemic.

HC Deb 28 June 2021 | PQ 20333

[Topical Questions](#)

Asked by: Jessica Morden

As current Government investment in motor neurone research is not the targeted funding that is needed, will the Minister meet charities, researchers and patients to examine this discrepancy and commit to additional funding of £10 million a year for five years for a virtual motor neurone disease research institute, with a specific focus on helping us to get a world free of MND?

Answering member: Helen Whately | Department: Health and Social Care

I will look into the hon. Lady's specific request, but I can tell her that the Government are actively supporting research into motor neurone disease. For instance, in April I jointly hosted a roundtable event on boosting MND research with the National

Institute for Health Research/Sheffield Biomedical Research Centre, which brought together researchers and others. We are absolutely committed to this area of work.

HC Deb 08 June 2021 | Vol 696 c818

[Motor Neurone Disease](#)

Asked by: Smith, Henry

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to support targeted research on motor neurone disease.

Answering member: Helen Whately | Department: Department of Health and Social Care

We are currently working on ways to significantly boost further research on dementia and neurodegeneration. On 29 April, I hosted a roundtable event on boosting motor neurone disease research with the National Institute for Health Research Sheffield Biomedical Research Centre. The event brought together researchers, charities, people with motor neurone disease and funders. We will be working closely with these stakeholders over the coming months to consider ways forward for this vital area of research.

HC Deb 27 May 2021 | PQ 3840

[Motor Neurone Disease: Research](#)

Asked by: Nichols, Charlotte

To ask the Secretary of State for Health and Social Care, if he will increase the allocation of funding from the public purse for motor neurone disease research to above £5 million per year.

Answering member: Edward Argar | Department: Department of Health and Social Care

Over the past five years, the Government has spent a total of £55 million on motor neurone disease (MND) research. In 2019/20, the Department, through the National Institute for Health Research, spent £2.7 million on MND research. Additionally, UK Research and Innovation, through the Medical Research Council, spent £13.4 million on MND research in 2019/20. We are currently working on ways to significantly boost further research on dementia and neurodegeneration, including MND.

HC Deb 28 April 2021 | PQ 186275

[Motor Neurone Disease: Research](#)

Asked by: Baker, Mr Steve

To ask the Secretary of State for Health and Social Care, what assessment he has made of the implications for his policies of the report entitled, Accelerating research for a treatment for motor neurone disease, published by the My Name's Doddie Foundation.

To ask the Secretary of State for Health and Social Care, with reference to My Name's Doddie Foundation's report entitled Accelerating research for a treatment for motor neurone disease (MND), if he will implement the recommendation of that report to fund £50 million over five years in a new MND Research Institute.

Answering member: Edward Argar | Department: Department of Health and Social Care

The Department has not made a specific assessment of the report. The Government is committed to supporting research into dementia and neurodegeneration, including motor neurone disease (MND). Over the past five years, the Department has spent over £9 million on MND research through the National Institute for Health Research. Additionally, UK Research and Innovation, through the Medical Research Council, has spent £45 million on MND research over the past five years. This includes research which aims to increase our understanding of the causes and genetic mechanisms of MND. We are currently working on ways to significantly boost further research on dementia and neurodegeneration at all stages on the translation pathway including medical and care interventions.

HC Deb 23 March 2021 | PQ 169847; PQ 169848

[Motor Neurone Disease: Research](#)

Asked by: Morden, Jessica

To ask the Secretary of State for Business, Energy and Industrial Strategy, pursuant to the Answer of 11 January to Question 130668, if he will name the projects that received funding in 2019-20 from the (a) Medical Research Council and (b) National Institute for Health Research.

Answering member: Amanda Solloway | Department: Department for Business, Energy and Industrial Strategy

The Medical Research Council (MRC) funded seven Motor Neurone Disease-related projects in 2019-20 in pursuant to the Answer of 11 January to Question 130668. Details of the projects can be found in the table below.

Research Organisation	Project Title	Start Date	End Date	Amount Awarded (£m)
University College London	The impact of TDP-43 on translation and the response to axonal damage in amyotrophic lateral sclerosis	01/10/2019	30/09/2024	£1.9m
University College London	Elucidating early stage ALS pathomechanisms that drive mitochondrial dysfunction	01/01/2020	31/12/2022	£0.9m
University of Sheffield	Regulation of ER-mitochondria contacts in neurodegeneration	01/07/2019	30/09/2022	£0.6m
University College London	A 5 year prospective follow-up clinical and imaging investigation of demyelinating clinically isolated syndrome (CIS)	01/09/2019	31/08/2023	£0.8m
Imperial College London	Regulated proteolysis of p62/SQSTM1, nutrient-sensing and human disease	01/02/2020	31/01/2023	£0.5m

University of Edinburgh	Investigating the molecular mechanisms of mutant C9orf72 human iPSC-derived astrocyte-mediated motor neuron deficits	01/08/2019	31/01/2022	£0.2m
Newcastle University	Novel MRI Biomarkers in Neuromuscular Disease	01/09/2019	31/08/2022	£0.1m

The National Institute for Health Research (NIHR) funded no Motor Neurone Disease-related projects during this period.

Further details of all projects funded by UK Research and Innovation (UKRI), which MRC has been integrated into, can be found at <https://gtr.ukri.org/>.

HC Deb 14 January 2021 | PQ 135876

[Motor Neurone Disease: Research](#)

Asked by: Morden, Jessica

To ask the Secretary of State for Business, Energy and Industrial Strategy, what steps his Department is taking to support research on motor neurone disease.

Answering member: Amanda Solloway | Department: Department for Business, Energy and Industrial Strategy

In 2019/20, UK Research and Innovation (UKRI), through the Medical Research Council (MRC), spent around £13.4 million on Motor Neurone Disease (MND) research. This included research which aims to increase our understanding of the causes and genetic mechanisms of MND and Amyotrophic Lateral Sclerosis (ALS) a form of MND. Over 5 years (2015/16 - 2019/20) MRC expenditure relevant to MND and ALS totalled £45 million.

In addition, UKRI, through the Biotechnology and Biological Sciences Research Council, supports a diverse portfolio of neuroscience research and innovation totalling around £30 million per annum. This work may underpin MND research by furthering current understanding of: the structure and function of the nervous system; cell biology and genetics; mental processes including learning and memory, and neurodegeneration as a result of normal ageing. Their portfolio of funded research also includes awards seeking to understand the biology of neuromuscular systems and motor control which has underpinning relevance to MND has an average annual spend of £1.2 million.

Additionally, the Department of Health and Social Care (DHSC) funds research through the National Institute for Health Research (NIHR). It is not usual practice to ring-fence funding for particular topics or conditions. The NIHR welcomes funding on applications for research into any aspect of human health, including MND. Applications are subject to peer review and judged on open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money, and scientific quality.

Over the past five years, DHSC has spent over £9 million on MND research through NIHR programmes and infrastructure. In 2018-19 alone, the NIHR invested £2.2 million in MND research through the NIHR research programmes and the NIHR Clinical Research Network. Additionally, the NIHR research infrastructure supported 73 research studies and trials on MND in 2018-19.

Furthermore, you be interested to hear about the NIHR Sheffield Biomedical Research Centre which has a research theme dedicated to MND. Further information on the AMBRoSIA study can be found at:<http://sheffieldbrc.nihr.ac.uk/research-themes/motor-neurone-disease/>.

HC Deb 14 December 2020 | PQ 126801

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Useful links and further reading

[Oxford Motor Neuron Disease Centre](#)

[Sheffield MND Care & Research Centre](#)

[UCL Motor Neuron Disease Centre](#)

[Euan MacDonald Centre for Motor Neuron Disease Research, University of Edinburgh](#)

UK Motor Neurone Disease Clinical Studies Group

[UK MND Research Studies](#)

University Hospital Southampton

[Pioneering motor neurone disease trial starts in Southampton](#)

5 March 2021

MND Scotland

[Scientists repair axons for first time](#)

18 January 2021

BBC News Online

[Motor neurone disease: Edinburgh scientists reveal breakthrough](#)

19 January 2021

My Name's Doddie Foundation

[Leading Research Into The Future](#)

27 November 2020

National Institute for Health Research

[New treatment for motor neurone disease shows promise in early trials](#)

13 July 2020

University of Sheffield

[New insights from first clinical trial of potential treatment for motor neurone disease](#)

8 July 2020

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