

How we got here

After months of dedicated campaigning by the United to End MND coalition, patients, charities, and researchers won a huge victory in November 2021 with the news that the Government would invest £50 million of new money over five years into targeted MND research.

The £50 million was the exact figure requested in the coalition's July 2021¹ submission to Government for the October Spending Review for the establishment of a virtual National MND Research Institute to instigate a comprehensive 5-year plan specifically for translational MND research to accelerate the discovery of treatments for this devastating disease.

Since the announcement, we have engaged with both the Department for Business, Energy, and Industrial Strategy (BEIS) and the Department of Health and Social Care (DHSC). We understand BEIS will provide 80% of the funds, with DHSC providing the remaining 20%. It is important to note that the money is not coming to the coalition itself, or any of its members.

We have invited the DHSC Secretary of State to a research lab where the commitment to funding can be emphasised and further discussed. We are also working with Gillian Keegan, the DHSC Minister for Care. In addition, the Secretary of State for BEIS is being pursued to ensure clarity on when and how the £50 million will be spent.

How do we want the £50 million Government funding to be spent?

In short, we want it spent on the detailed scientific plan set out in the government spending review submission.¹ It is important to highlight that no part of the £50m will be spent on care research, which will continue to be applied for through existing government channels as a separate endeavour.

What else is happening while we await delivery of the investment?

In January 2022 scientists and patients submitted a separate, detailed grant request to a new "Collaborative MND Partnership", as described in the November 14th 2021 announcement.² While this is a separate submission, the projects contained within it are foundational and vital components of the full comprehensive plan for the £50m.

This application for £4.25m of funding is co-ordinated by the charity, LifeArc, and includes other contributors including the MND Association, MND Scotland, My Name's Doddie Foundation and the Government.

It should be noted that the majority of this funding comes from the charities. The £1m government portion is totally separate from its £50m commitment, providing an additional demonstration of the considerable

¹ <https://patientsunited2endmnd.files.wordpress.com/2021/10/mndresearchinstitute-2021-spendingreviewsubmission-final.pdf>

² <https://www.gov.uk/government/news/government-to-invest-375-million-in-neurodegenerative-disease-research>

influence of the campaign. It is expected that the project funding will be approved by the end of March 2022.

The coalition hopes - and strongly recommends - that the new innovative management and governance structure proposed for this new partnership will be the model for the £50m government investment. We believe it demonstrates that the UK MND community is ready to direct the £50m into high impact research to accelerate us towards a cure for MND.

The initial projects covered by the £4.25m Collaborative MND Partnership have two major aims.

1 - the creation of a streamlined process for identifying the most promising drugs for clinical trials by setting up a national network of human cell-based testing labs – the first of its kind in the world.

2 - a change in the way people living with MND participate in research and how we conduct clinical trials. The national network will provide opportunities for access to trials to a higher number of people wherever they live, using low burden, patient-centred, remote technologies wherever possible. This will also result in important answers regarding effectiveness of new drugs being delivered far more quickly than is currently the case.

Next steps - focusing government on a single application for a single plan with a £50m grant

With the Collaborative MND partnership proposal submitted, we are now engaging with government on the speedy delivery of the core £50m funding so that the rest of the plan can be implemented.

We will not be waiting for completion of the projects mentioned above to press further forward. We are asking the government to confirm commitment to the detailed plan as soon as possible, ideally within the first half of 2022.

We are asking government to accept that the most efficient way to achieve the coordinated national infrastructure required for this groundbreaking project is via an additional *single application*³ to be submitted as soon as possible after the initial components approval. The crucial aims of this groundbreaking submission concept are:

- **Address the lack of efficiency, coordination and confidence** engendered by the existing multiple application processes that would typically be needed for such a plan.
- **Signal to industry** that the **UK** is a global leader in neurological disease research, thus attracting international investment and partnerships.
- **Improve responsiveness** to new knowledge, ensuring the prevention of delays.

We are also emphasising that the researchers' plan is perfectly aligned with the government's own Office for Life Sciences vision⁴ to make the UK a "scientific superpower".

³ <https://patientsunited2endmnd.files.wordpress.com/2022/02/united2endmnd-single-application-process-1.pdf>

⁴ <https://www.gov.uk/government/publications/life-sciences-vision>

Discussions with BEIS and DHSC are continuing. Once we have their agreement, we will set out further details of plans for the next 5 years including objectives, patient involvement, timelines and reporting.

We look forward to our vision becoming a reality, so that the hope of a cure for this dreadful disease can be nourished and nurtured.

The United 2 End MND coalition