



The Rt Hon Sajid Javid MP
Secretary of State for Health and Social Care
Department of Health and Social Care
39 Victoria Street
London SW1H 0EU

The Rt Hon Kwasi Kwarteng MP
Secretary of State for Business, Energy and Industrial Strategy
Department for Business, Energy and Industrial Strategy
1 Victoria Street
London SW1H 0ET

Dear Secretaries of State,

We are writing to you as a group of people living with MND who have been actively involved in the [#United2EndMND](#) campaign for improved and specifically targeted Government funding for translational MND research.

We were, of course, delighted at the Prime Minister's November 14 announcement that £50 million additional funding would be set aside over the next five years for a MISSION based on the detailed scientific plan that 12 leading MND neuroscientists at 22 centres across the UK had submitted to the Government's 2021 spending review.

It is now 6 months since that promise and not a single penny has been received to enable the scientists to begin their vital work. As you know, time does not wait for those living with this devastating, terminal condition and the hope that the November announcement gave rise to in our community is now slipping away to be replaced by despair.

We believe that the key barrier to progress is unnecessary red tape and bureaucracy. This is not in line with the more streamlined processes currently being promoted in your departments. We understand that your departments are trying to find "*ways to simplify and streamline... processes*" and, at the same time, to introduce "*a single application and award management system*" as part of an independent review of research bureaucracy initiated by BEIS."

Our coalition of charities, researchers and patients have proposed a robust management and oversight structure for a virtual MND Research Institute to receive the funding and to put it to work in the most efficient way. However, we understand that NIHR and MRC are still insisting on a multi-application process. If this is the case, then this is effectively reneging on the Government's promise of a "Mission", because the work described in the detailed plan could not

be carried out within 5 years and not in the co-ordinated way described. Instead, the scientists will have to waste more precious time, potentially **years**, on unnecessary paperwork.

As Professor Christopher McDermott of Sheffield University recently said on BBC Breakfast, keeping to the current application process will mean the arrival of the first meaningful treatments that our scientists believe are so close will be put back by “decades, not years.”

It’s also worth pointing out that the investment from the major scientific research and pharmaceutical companies that we envisaged in our plan is unlikely to be forthcoming without the confidence that our co-ordinated plan will encourage.

Given the acute disappointment among MND patients and carers that absolutely no funding has yet been received, we now ask you to ensure that your department commits the promised funds to our detailed scientific plan via a SINGLE APPLICATION process and that the first £10 million of funding is awarded and in place by November 14, the first anniversary of the Prime Minister’s promise.

Please do not take away the hope that your government’s promise has engendered in the MND patient and carer community and join with us to ensure a world free from this awful disease.

Yours sincerely,

Chris Johnson

Lee Millard

Emma Moss

David Setters

Nicola Waters

<https://patientsunited2endmnd.org/>

Who we are - <https://patientsunited2endmnd.org/who-are-we/>