

UK MND Research Institute - help ensure the £50m funding promise is delivered

United 2 End MND working with the leading charities & researchers

Nearly 2 years after Government promise, barriers to efficient access to funding remain

Despite efforts to improve the situation, patients behind the United to End MND* campaign continue to feel let down by Government on the most efficient ways for leading UK neuroscientists to draw down £50m funding promised in November 2021. Recently, further delays have emerged regarding access to a substantial chunk (£20.5m) of the £50m investment.

There appears to be no new money and no ring fencing for MND as promised

From recent discussions with MRC officials, it is clear there is no new money and the funds are not ring fenced. MND researchers will have to compete for existing funds with other diseases. This will disrupt their co-ordinated scientific plan and tie them up in red tape preparing multiple applications that may not be successful, significantly delaying progress towards the treatments we need.

How can I help? - We are asking MPs if they can help us with this issue. A briefing note is below.

To be clear, this is independent of the scientists and charities who need to maintain cordial relationships with Government. Talks are ongoing and there seems to be a better understanding of the issues at both the DHSC and DSIT. However, as patients living with MND, time is at a premium. We have spent well over 3 years on this to be continually thwarted by bureaucratic delays. We wish to spend more time making memories with our families!

David Setters, Lee Millard and Nicola Waters <https://united2endmnd.org/>

Briefing Notes

1. Effectively, **officials are un-coordinating an already coordinated plan** devised by neuroscientists across 20+ research centres by sticking doggedly to a "piecemeal" grant application process which will tie them up in red tape. We would prefer them to be at work in the laboratory. <https://united2endmnd.org/2023/02/02/our-speech-today-at-steve-barclays-ministerial-mnd-roundtable/>

2. We are **now** calling on Steve Barclay at DHSC and Chloe Smith/George Freeman at DSIT to help us negotiate this impasse not only to rekindle the hope we were given, but also

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provide certainty to the research centres, so they can invest in vital staff and resources and to become that scientific superpower we often hear about.

3. **DSIT seem to be causing the current blockage.** 80% of the funding was always expected to come from DSIT (previously BEIS) via the Medical Research Council (MRC). The DHSC 20% is now being delivered and Steve Barclay has undertaken to talk to ministerial colleagues about the remainder so that the Government promise he reiterated in the House of Commons on September 5, 2022 is kept.

*"Following work over the summer between my Department and the Department for Business, Energy and Industrial Strategy, through the National Institute for Health and Care Research and UK Research and Innovation, **to support researchers to access funding in a streamlined and coordinated way, we are pleased to confirm that this funding has now been ring-fenced.** The Departments welcome the opportunity to support the MND scientific community of researchers as they come together through a network and linked through a virtual institute."*

Steve Barclay – Sept 2022.

4. Contrary to this statement, it became clear to Prof Al Chalabi and colleagues at a recent meeting called by senior MRC officials to develop the "**streamlined and coordinated way**" that no such "**ring fenced**" funding was available to them.

5. DHSC is delivering on its 20% portion of the investment and may soon announce an exciting development. **While we welcome this, it should not divert attention from the delivery of the remaining funds by the DSIT in the efficient way we need.**

**We work closely with the Burrow family, Stephen Darby, Marcus and Louise Stewart, Ed Slater, My Name5 Doddie Foundation, MND Association, MND Scotland, Lifearc and the scientists.*