

Gillian Keegan MP  
Minister for Care and Mental Health  
Department of Health and Social Care  
39 Victoria Street  
London SW1H 0EU

22 April 2022

Dear Minister,

The United to End MND coalition of patients, scientists and charities is due to meet with you on 26 April (and at a later date at BEIS) to discuss the delivery of the promised £50m wholly new government investment in MND research announced in November 2021. We are immensely grateful for the time you are investing in this important issue and for your commitment to tackling this horrific disease.

We are a group of scientists representing the leading MND research centres in the UK and collaborating in the fight to bring an end to MND. We have submitted a detailed scientific plan to achieve this. The plan coordinates 5 years of work across 5 universities and 22 research centres. Our aim is to give hope to the patients we see in our clinics every day, giving them the opportunity to take part in trials that offer a real chance of disease-modifying treatment.

Central to achieving the proposed coordinated national infrastructure for this ground-breaking project is efficient, responsive and rapid access to the assured funds via a **single peer-reviewed application**. This can only be achieved via such a grant application process. The benefits are as follows:

- The model of a single peer-reviewed application for a body of work is simple, efficient and has a proven track record (e.g. DRI, BRCs), versus the business as usual, multiple applications which risks fracturing the single coordinated approach.
- Full reliable funding over the 5 years, without having to reapply repeatedly, frees us to do science, not chase endless and extremely time-consuming applications and better supports retention of key staff. The cash flow could be released at predetermined time points (e.g. annually) according to the approved work-plan.
- Funding of a body of national (across whole of the UK) collaborative<sup>1</sup> work signals to industry and the MND community that the UK is serious in its ambition to become a leader in the development of novel and effective treatments and thus attract significant industry investment.

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<sup>1</sup> this has already begun, with the recent submission from the newly formed MND Partnership of the NIHR, UK Research and Innovation (UKRI), LifeArc, MND Association, My Name's Doddie Foundation and MND Scotland – A £4.25m foundational project for the Virtual MND Institute - including £1m of proposed government funding.

We are aware that you are looking to make research administration more efficient, including the “one NIHR” programme, and we hope that we might help provide a model for that.

We understand first hand the impact of this devastating disease, as we care for patients alongside our research. We want to change the conversation we have with those living with the disease and, in the near future, to be able to offer them effective treatments. We look forward to hearing the outcome of your forthcoming meetings with the coalition.

Yours sincerely,

***Professor Ammar Al-Chalabi***

NIHR Senior Investigator and Professor of Neurology and Complex Disease Genetics,  
Department of Basic and Clinical Neuroscience, King’s College London

***Professor Christopher McDermott***

NIHR Research Professor and Professor of Translational Neurology - Sheffield Institute for Translational Neuroscience (SITraN), Department of Neuroscience, University of Sheffield

***Professor Dame Pamela Shaw***

Professor of Neurology, Honorary Consultant Neurologist, Sheffield Teaching Hospitals NHS Foundation Trust, Director of the Sheffield Institute for Translational Neuroscience (SITraN), Director Sheffield NIHR Biomedical Research Centre for Translational Neuroscience. Director of the Neuroscience Research Institute, University of Sheffield

***Professor Siddharthan Chandran***

Dean of Clinical Medicine, Director of Centre for Clinical Brain Sciences, Edinburgh Neuroscience, Euan MacDonald Centre and Anne Rowling Regenerative Neurology Clinic

***Professor Linda Greensmith***

Institute of Neurology, University of London

***Professor Andrea Malaspina***

Institute of Neurology, University of London

***Professor Kevin Talbot***

Head of Department Nuffield Department of Clinical Neurosciences - University of Oxford

***Professor Martin Turner***

Professor of Clinical Neurology & Neuroscience – University of Oxford

***Professor Janine Kirby***

Professor of Neurogenetics, Sheffield Institute for Translational Neuroscience (SITraN),  
University of Sheffield

***Professor Khuloud Al-Jamal***

King's College London

***Professor Chris Shaw***

Professor of Neurology and Neurogenetics - Director, Maurice Wohl Clinical Neuroscience  
Institute, Associate Director UK Dementia Research Institute, Institute of Psychiatry,  
Psychology and Neuroscience - King's College London and King's Health Partners

***Professor Carolyn Young***

Professor of Neurology, The Walton Centre, Liverpool.

***Dr Brian Dickie***

Director of Research Development, MND Association

***Dr Jane Haley MBE***

Head of Research – MND Scotland

***Sean McGrath***

Medical Strategy Lead – My Name's Doddie Foundation @

Cc The Rt Hon Sajid Javid MP