

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) collaborative¹ work signals

¹ 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

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.

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

and MND Scotland – A £4.25m foundational project for the Virtual MND Institute - including £1m of proposed government funding.

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