MND Translational Research Institute - Why we need a new approach to funding

The United2EndMND coalition are grateful for all discussions to date. However, we are very concerned that the extent of current targeted MND[1] Research funding is misunderstood. Along with this critical element, we summarise briefly why we believe now is the right time for a new model of funding. Thank you for your attention.

Current level of funding is only £5m or less a year. An example of the misunderstanding is the figure of **£15.9m** quoted by Kwasi Kwarteng (in Parliament on 21/09/21) as being spent by the MRC in 2019/2020. This figure is not targeted at MND. Over £7m of this number (from the publicly available database) are capital grants given to dementia research, and about £3m is further general neurodegenerative disease research. Another figure often quoted is that £50m to £60m has been spent over the last 5 years. On the same assessment, the amount of targeted MND research, we estimate, is only in the region of up to £20m. Any increase in funding, as promised by the Prime Minister in June 2021, must be considered with these figures in mind.

MND research has made considerable progress in recent years. Research grants have supported work into specific aspects of the disease to increase understanding to a point where we now have treatment targets. These are single centre or small collaborations into narrow research questions.

The challenge now is different - to bring this understanding together and turn discoveries into treatments (translational research). Indeed, the Government's Life Sciences Vision recognises the need to "accelerate the pace of translational studies" and envisages a new translational research model for neurodegenerative diseases along the lines of the UK Dementia Research Institute[2]. This is exactly the model we are calling for as it allows for transformational collaboration.

£50m funding is needed to create the infrastructure to bring research teams across the UK together (initially five universities) - each of which has expertise in different aspects of the translational pathway. In addition, this funding will deliver: a national MND biobank, the high performance computing infrastructure for genetic studies, lab work to create cellular models, identification of drug targets, protocols for drug selection and testing, an innovative new trial platform, training and development, understanding of the interface with other diseases such as dementia.

This is an ambitious research programme that cannot be undertaken by applying for narrow research grants into specific issues. Relying on such an approach would mean decades before any meaningful treatments. Thousands of patients will continue to die from this terminal illness. The UK will likely be overtaken by scientists in the US and Europe.

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[1] MND – encompasses ALS, PMA, PLS, PBP and Kennedy's Disease

[2] Page 46-47 of the Life Sciences Vision

With appropriate investment, the UK can innovate a new approach to neurodegenerative diseases, **strengthen our position as a science superpower**, gain £millions of investment (at least two pharmaceutical companies are interested in investing and talking to Government) - and bring an end to one of the most horrific diseases.