Open letter to the Prime Minister - 28/01/2026

Dear Prime Minister,

I am writing both as an experienced GP and as step-mother to Lillia, a 19-year-old with SOD1 related Motor Neurone Disease (MND), and on behalf of families and individuals living with MND across the UK.

MND is a fatal neurological disease. Every patient will lose function: mobility, speech, swallowing and breathing before dying from the condition. One third die within a year; half within two. 1 in 300 people will develop MND in their lifetimes.

For decades, there was no treatment. Now, for people with SOD1 MND, there is.

Tofersen is MHRA-approved and is being supplied free of charge by Biogen while NICE completes the appraisal. Yet some patients are still not receiving it, not because the drug is unavailable, but because some local NHS bodies are refusing to fund its administration.

As a result, some patients are receiving treatment and others are not, based solely on postcode and local resource decisions. This is a profound and unacceptable health inequality. The worst injustice I have experienced in my 30 year medical career.

What makes this situation even more troubling is that it is not new. The Motor Neurone Disease Association, My Name'5 Doddie Foundation and the All-Party Parliamentary Group on MND have been discussing Tofersen access for at least 2 years. Despite this, no effective national solution has been implemented. During this time, patients have deteriorated and some will have lost the opportunity to benefit at all.

For a rapidly progressive, fatal disease, this disparity is not just unfair, it is cruel and inhumane. Every delay causes irreversible loss of function.

We have raised this with ministers and have repeatedly been redirected to local systems. Local systems state this is a national issue. Meanwhile, patients decline.

This is a failure of leadership.

We are asking you and the Secretary of State for Health and Social Care, Wes Streeting, to intervene and provide time-limited national funding so that all people diagnosed with SOD1 MND can access Tofersen within six weeks of diagnosis, regardless of where they live.

If this were cancer, such inequality would be unthinkable.

These patients do not have time to wait for bureaucracy to resolve itself. Tofersen directly targets the underlying genetic driver of SOD1 MND, slowing the biological

process that destroys motor neurones. For the MND community, it is the first credible evidence that MND can be treated, not just managed, until death.

I am ready to meet you or the Health Secretary anywhere, at any time.

Please act now to prevent avoidable disability and death.

Yours sincerely,

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Co-signatories

Geoff Burrow *- father of Rob Burrow CBE*

Kevin Sinfield CBE *- former England rugby international - one of the most powerful global MND advocates inspired by his friendship with Rob Burrow*

Professor Ammar Al-Chalabi *- Professor of Neurology and Complex Disease Genetics, King's College, London*

Professor Christopher McDermott *- Professor of Translational Neurology, University of Sheffield*

Professor Dame Pamela Shaw *- Professor of Neurology, University of Sheffield*

Professor Andrea Malaspina *- Professor of Neurology UCL Queen Square Institute of Neurology*

Tanya Curry *- CEO MND Association (www.mndassociation.org)*

Nicola Roseman *- CEO My Name'5 Doddie Foundation (www.myname5doddie.co.uk)*

Lee Millard, David Setters, Luke Hames-Brown, Ben Lighting – all living with MND (www.United2EndMND.org)