The Hon Mark Butler MP
Minister for Health and Ageing; Minister for Disability and the NDIS
Parliament House
Canberra ACT 2600
E: minister.butler@health.gov.au

Dear Minister Butler,

I am writing to urge the Australian Government to invest in a national motor neurone disease (MND) database to address a critical gap in our understanding of this devastating disease.

Right now, we simply don’t know enough about MND in Australia, and the data collected is fragmented over several smaller datasets. A unified national database would give us critical insights into how the disease is affecting Australians — including how many people are living with MND, where they are, when they were diagnosed, and how the disease progresses over time. This data is essential to improving care, advancing research, and ultimately finding a cure.

MND Australia’s recent report, *Every Moment Matters – Addressing the human and economic toll of motor neurone disease in Australia*, identified **an integrated national data registry and database as the top priority**. Establishing this resource would drive evidence-based decision-making, enable more targeted and effective research, and ultimately improve care and outcomes for people living with MND, and reduce the 5 billion dollar impact the disease has on the Australian economy.

Other recommendations from the report request government investment to:

* establish a nationally consistent funding pathway to fund care and support for people living with MND, irrespective of age. supports research and care in Australia.
* support MND Australia to develop a national directory of healthcare professionals with MND experience, with funding provided by the government.
* fund MND Australia to develop a National MND Support Program targeted at people living with MND and their carers.

<insert your short personal story here on how MND has impacted your life or someone you love or provide care for>

MND Australia, as the national peak body, is championing the development of a comprehensive data strategy on behalf of the MND community. I strongly encourage you to engage with their CEO, Clare Sullivan, to discuss this issue further: clare.sullivan@mndaustralia.org.au

The more we understand MND and its impact in the Australian context, the closer we get to meaningful breakthroughs — whether in treatment, care, or even prevention.

Thank you for your attention to this urgent and important matter.

Kind regards,