Template letter to Minister Butler

**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.

Currently, MND is not a notifiable disease in Australia, meaning we lack even the most basic data — including how many Australians are living with MND, their age at diagnosis, their location, and how the disease progresses. This absence of nationally coordinated data hampers our ability to advance research, plan services, and ensure Australians living with MND receive the best possible care.

MND Australia’s recent economic impact report into MND, *Every Moment Matters*, identified a national data registry and database as a 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.

<insert your 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](mailto: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,

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