

**Government response to the Petitions Committee Report to the
petition of Paul Barton: Make Motor Neurone Disease a Notifiable
Disease**

Presented to the House of Representatives

In accordance with Standing Order 256

Government response to the Petitions Committee Report to the petition of Paul Barton on making Motor Neurone Disease a Notifiable Disease

Introduction

1. The Government has carefully considered the report of the Petitions Committee (the Committee) published 7 November 2025 on the petition: "Make Motor Neurone Disease a Notifiable Disease."
2. The Government responds to the Committee's report in accordance with Standing Order 256. This response is tabled in accordance with Standing Order 381.

Request from petitioner

3. The petitioner asks the House of Representatives to request the Minister of Health to designate motor neurone disease as a notifiable disease under the Health Act 1956. This would require health practitioners to report cases of motor neurone disease to the Medical Officer of Health.
4. The petitioner's rationale is that New Zealand has the highest incidence of motor neurone disease in the world, yet there is no mandatory reporting. He believes that making motor neurone disease notifiable would enable better data collection and research into environmental and occupational risk factors, ultimately improving understanding and outcomes for people with motor neurone disease.

Petitions Committee Report

5. The Committee acknowledged the concerns raised by the petitioner and the important issues highlighted about the need for improved data collection and research into motor neurone disease.
6. The Committee noted that the primary purpose of designating a disease as notifiable is to enable a public health response to conditions that pose an outbreak risk or require immediate intervention. Motor neurone disease does not meet these criteria, as it is not infectious, and there are currently no measures to prevent or control the disease at the individual case level.
7. The advantages of improved surveillance and data achieved for notifiable diseases need to be balanced against the disadvantages such as the intrusion into patient privacy and increased workload for health professionals.
8. The Committee recommended that the Ministry of Health work with the New Zealand Motor Neurone Disease Registry to enable the collection and analysis of occupational and environmental factors that potentially contribute to New Zealand's high incidence of motor neurone disease.

Response

9. The Government acknowledges the devastating impacts that motor neurone disease has on patients and their families.
10. The Government does not intend to make motor neurone disease a notifiable disease, but notes that there may be other avenues for improving data collection and surveillance.
11. The Ministry of Health is available to work with the owners of the motor neurone disease registry to consider opportunities to improve collection of occupational and environmental factors which may contribute to the incidence of motor neurone disease, noting that:
 - a. the registry is funded and maintained by Motor Neurone Disease New Zealand
 - b. the register is voluntary with no legislative requirements for clinicians or patients to participate.