

29 May 2023

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Tēnā koe Amy

**Your request for Official information, reference: HNZ00017846**

Thank you for your email on 18 May 2023, asking for the following which has been considered under the Official Information Act 1982 (the Act).

Please find a response to each part of your request below.

*"I would like to know more about the prevalence of Lou Gehrig's Disease (also known as Amyotrophic Lateral Sclerosis or ALS) and Motor Neuron Disease (MND) in New Zealand. Specifically, I am seeking the following information: The total number of New Zealand-born citizens who are currently living with Lou Gehrig's Disease (ALS) or Motor Neuron Disease (MND).*

*If there are differences between Lou Gehrig's Disease (ALS) and Motor Neuron Disease (MND), please provide the total number of people living with each condition separately.*

*A demographic breakdown of people living with Lou Gehrig's Disease (ALS) or Motor Neuron Disease (MND), including age distribution and any known risk factors or causes of the disease.*

*Historical data on the prevalence of Lou Gehrig's Disease (ALS) or Motor Neuron Disease (MND) in New Zealand, particularly any observed trends in the number of cases and any potential reasons for these trends."*

This part of your request is refused under 18(g) of the Act, as the information requested is not held by Te Whatu Ora, and we don't have grounds to believe it is held by any other entity subject to the Act.

*"A clarification on whether Lou Gehrig's Disease (ALS) is the same as Motor Neuron Disease (MND) or if there are any differences between the two conditions."*

Motor neuron diseases are a group of progressive neurological disorders that destroy motor neurons, the cells that control skeletal muscle activity such as walking, breathing, speaking, and swallowing. This group includes diseases such as amyotrophic lateral sclerosis, progressive bulbar palsy, primary lateral sclerosis, progressive muscular atrophy, spinal muscular atrophy, Kennedy's disease, and post-polio syndrome. Further information can be found at various websites here: <https://healthify.nz/health-a-z/m/motor-neurone-disease/>, and <https://neurological.org.nz/conditions/brain-disorders-and-support/motor-neuron-disease-als/>.

## How to get in touch

If you have any questions, you can contact us at [h.nzOIA@health.govt.nz](mailto:h.nzOIA@health.govt.nz).

If you are not happy with this response, you have the right to make a complaint to the Ombudsman. Information about how to do this is available at [www.ombudsman.parliament.nz](http://www.ombudsman.parliament.nz) or by phoning 0800 802 602.

As this information may be of interest to other members of the public, Te Whatu Ora may proactively release a copy of this response on our website. All requester data, including your name and contact details, will be removed prior to release.

Nāku iti noa, nā



Duncan Bliss  
**Group Manager, Planned Care  
Hospital and Specialist Services**