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16 May 2023

Amy Ferguson

By email: fyi-request-22556-dc6c568a@requests.fyi.org.nz

Ref: H2023025230

Tēnā koe Amy

Transfer of your request for official information

Thank you for your request under the Official Information Act 1982 (the Act) to Manatū Hauora (the Ministry of Health) on 25 April 2023. You requested:

- "1. The total number of New Zealand-born citizens who are currently living with Lou Gehrig's Disease (ALS) or Motor Neuron Disease (MND).
- 2.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.
- 3. 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.
 4. 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.

5. 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."

The requested information is held by Te Whatu Ora – Health New Zealand. For this reason, I have decided to transfer your request to their agency under section 14(b)(i) of the Act. You can expect a response from Te Whatu Ora in due course. Please accept our apologies for the delay in transferring your request.

Under section 28(3) of the Act, you have the right to ask the Ombudsman to review any decisions made under this request. The Ombudsman may be contacted by email at: info@ombudsman.parliament.nz or by calling 0800 802 602.

Nāku noa, na

Manager, OIA Services

Government and Executive Services | Te Pou Whakatere Kāwanatanga

COPY OF OIA REQUEST

From: Amy Ferguson <fyi-request-22556-dc6c568a@requests.fyi.org.nz>

Sent: Tuesday, 25 April 2023 05:34 **To:** OIA Requests < oiagr@moh.govt.nz >

Subject: Official Information request - Lou Gehrig's Disease (ALS) and Motor Neuron Disease

(MND)

Dear Ministry of Health,

I am writing to request information under the Official Information Act 1982 (OIA). 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:

- 1. The total number of New Zealand-born citizens who are currently living with Lou Gehrig's Disease (ALS) or Motor Neuron Disease (MND).
- 2.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.
- 3.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.
- 4.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.
- 5.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.

I understand that under the OIA, I should receive a response to my request within 20 working days of the date it was received. If my request is too broad or unclear, please contact me so that I can provide any necessary clarification.

Thank you for your assistance in this matter.

Sincerely,

Amy Ferguson