



New Zealand House of Representatives
Te Whare Māngai o Aotearoa

Petitions Committee

Komiti Whiriwhiri Take Petihana

54th Parliament

November 2025

Petition of Paul Barton: Make Motor Neurone Disease a Notifiable Disease

Presented to the House of Representatives
by Greg O'Connor, Chairperson

Contents

Recommendation.....	3
Request to designate MND a notifiable disease.....	3
Motor neurone disease	3
Notifiable diseases.....	3
Comments from the petitioner	4
The petitioner's experience of MND.....	4
Incidence of MND in New Zealand	4
The petitioner's advocacy to make MND a notifiable disease	5
Other studies showing an environmental link.....	6
Financial costs of MND.....	6
Comments from the Ministry of Health	7
Our response to the petition	8
Appendix.....	9

Petition of Paul Barton

Recommendation

The Petitions Committee has considered the petition of Paul Barton—Make Motor Neurone Disease a Notifiable Disease—and recommends to the Government that the Ministry of Health work with the New Zealand MND Registry to enable the collection and analysis of occupational and environmental factors that potentially contribute to New Zealand’s high incidence of MND.

Request to designate MND a notifiable disease

The petition was signed by 2,568 people. It was presented to the House by Dr Vanessa Weenink on 23 July 2024 and requests:

That the House of Representatives request the Minister of Health to designate Motor Neurone Disease a ‘Notifiable Disease’, which means that upon diagnosis a health practitioner must report it to the Medical Officer of Health.

Motor neurone disease

Motor neurone disease (MND) affects nerves in the brain and spinal cord (motor neurones) that communicate with muscles. As these cells stop working, the muscles that help people to move, speak, breathe, and swallow stop working. It is a fatal, progressive disease, for which there is currently no cure. The average life expectancy for people diagnosed with MND is 3–5 years; however, 5–10 percent of people with MND live for a decade or more.

Notifiable diseases

The designation of a disease as a notifiable disease means that health practitioners and laboratories are required to report any suspected or diagnosed cases of that disease to the medical officer of health. In some cases, notifiable diseases must also be reported to local authorities. Most, but not all, notifiable diseases are infectious diseases. Diseases are designated as notifiable so that public health authorities can monitor and respond to outbreaks of diseases that risk public health.

Infectious notifiable diseases are outlined in Schedule 1 of the Health Act 1956, while Schedule 2 of the Act lists other notifiable diseases and conditions that are not infectious. The Act provides that the Governor-General, by Order in Council, can add or omit diseases from the schedule. MND is not listed as a notifiable disease or condition in either Schedule 1 or 2 of the Act.

The petitioner would like MND to be notifiable so that data is recorded that might help in understanding the illness—and potentially finding a cure for it.

Comments from the petitioner

We met with the petitioner, Paul Barton, and his wife Ally who was diagnosed with MND in 2020 at the age of 34. We thank Mr and Mrs Barton for their willingness to share their experience of MND with us.

The petitioner's experience of MND

While living in Sydney, the Bartons' bedroom was fumigated three times in six weeks for bed bugs. Six months later, Mrs Barton noticed that her right ring finger was tingling. This spread to her right arm, and by May 2020, weakness began affecting her lower limbs. The Bartons were married in August 2020. We were told that Mrs Barton felt that her COVID-19 vaccination the following year "sped things up". Within a couple of months, she had difficulty walking and talking. She was diagnosed with MND in 2021. Mrs Barton is one of the youngest people diagnosed with MND in New Zealand.

The petitioner told us that, before his wife became unwell, they were both working full time. Mrs Barton, a former ICU nurse, is no longer able to work, and Mr Barton has become her full-time caregiver. He said his wife is no longer able to do many things for herself. Her speech declined in 2022, and she now uses a grid pad and eye gaze to communicate.¹ At the time of our hearing, she could operate a wheelchair and walk some steps with the aid of a walking frame or with her husband's assistance.

Mr Barton told us that there is no cure for MND, which is difficult news for a person who receives an MND diagnosis. He said that when he asks questions about the disease, "we don't know" is the usual answer. He said that he would accept that answer if he felt that medical authorities and decision-makers were taking action to change that. However, he feels that is not the case. He particularly felt concerned when he learned there is no legal requirement to report MND cases.

Mr and Mrs Barton's experience is that many people are reluctant to talk about MND. Mr Barton said his wife described it eloquently when she said that in living with MND "you die socially before you die literally". We heard that people diagnosed with MND can feel that no one is listening to them. Mrs Barton told us, through her grid pad, that people with MND feel their voices have been taken away by the disease.

The Bartons would like more open discussions about MND to occur. They said they are fortunate to live in one of the few parts of New Zealand which has an MND Support Group, which is organised by a patient for other patients.

Incidence of MND in New Zealand

Mr Barton told us that an average of 144 New Zealanders each year are diagnosed with MND. Around 400 New Zealanders live with MND and an average of two people die each week from it.

¹ A grid pad is a touch screen tablet that assists people with conditions that affect speech and mobility to form sentences by selecting pictures and words. Eye gaze technology is used to see where a person is looking on a computer screen. This can allow them to select words and pictures, and to use apps, for example to listen to music or to send emails.

A 2018 study found that New Zealand has the highest rate of MND in the world.² The petitioner drew our attention to research by Dr Grace Chen of Massey University. A study by Dr Chen in 2019 found associations between MND and occupations in agriculture, as well as other occupations.³ Her further research indicated that pesticides and fumigants are associated with increased MND risks.⁴

The petitioner's advocacy to make MND a notifiable disease

Making a disease notifiable means that health practitioners are required to report cases. Mr Barton said this means that factors related to the disease are documented and used in developing a response to it. He told us that making a disease notifiable is the beginning of understanding it. He believes that, compared to the costs of managing MND, collecting and recording more information about it is affordable and achievable.

We asked the petitioner whether MND is a notifiable disease in any other country. He told us that it is not currently notifiable in any country in the world. He said that, because New Zealand has the highest rate of MND in the world, it has both an opportunity and an obligation to understand what factors are causing it.

Motor Neurone Disease NZ runs the New Zealand MND Registry in association with Otago University.⁵ The petitioner said registration by patients with MND is voluntary, so not every case is registered. He said this means that information about a person's occupation, location, environment, and other risk factors is not collected or analysed. He feels it is unreasonable to leave the decision to sign up to the register to people who have just been told that they have a life expectancy of 1–3 years. The petitioner would like to see, at a minimum, that registration of newly diagnosed MND patients is on an "opt-out" basis rather than "opt-in" as at present.

Mr Barton said deaths per year from MND have doubled from 75 deaths in 1992 to 159 deaths in 2020. He said that as the number of people with MND rises each year, he believes action to prevent its impact is critical. He told us that, when he was collecting signatures for his petition, many people told him they were shocked to learn that MND is not currently designated as a notifiable disease.

Notifiable diseases listed in Schedule 1 of the Health Act are infectious diseases; however, there are six non-infectious conditions listed as notifiable in Schedule 2 of the Act. The New Zealand Institute for Public Health and Forensic Science produces an annual *Notifiable diseases annual surveillance summary report*.⁶ It includes reporting on four of the six listed notifiable non-infectious conditions. The petitioner said that, in the 2021 report, notifications

² [Global Burden of Disease 2023: Findings from the GBD 2023 study](#), as cited in news article: [New Zealand has world's highest death rate from motor neuron disease - study | Stuff](#) 27 November 2018.

³ [Occupation and motor neuron disease: a New Zealand case-control study - PubMed](#).

⁴ [Occupational exposures to pesticides and other chemicals: a New Zealand motor neuron disease case-control study - PubMed](#).

⁵ More information about the MND Registry is available on the website of [Motor Neurone Disease NZ](#).

⁶ Notifiable diseases annual surveillance summary reports are available on the [website of the New Zealand Institute for Public Health and Forensic Science](#). These reports include four of the six notifiable non-infectious diseases: cysticercosis, decompression sickness, taeniasis, and trichinosis. They do not include the other two notifiable non-infectious diseases: Lead absorption and Poisoning from chemical contamination of the environment.

of those four conditions were either zero or in single figures. He contrasted that with 138 deaths from MND in the same year.

Poisoning arising from chemical contamination of the environment is one of the six non-infectious notifiable conditions listed as notifiable in Schedule 2 of the Act. Mr Barton noted again the connection made by Dr Chen between MND and agricultural work, as well as pesticide and fumigant use.

Other studies showing an environmental link

The petitioner said that there is not one universal cause of MND, as the age of the onset of the disease and the progression of symptoms vary from person to person. However, he said more studies are showing that location, occupation, and chemicals can have an influence.

In addition to the New Zealand research mentioned, Mr Barton referred to several other studies:

- A 2015 study found an association between accumulated lead emissions from gasoline and MND deaths in Australia.⁷
- A 2020 study of ALS (a form of MND) in four Italian provinces reported the potential role of environmental and occupational factors in incidence of the disease. Agricultural occupations and environmental exposure to pesticides, particularly fungicides, were among the factors considered.⁸
- A 2022 study of workers exposed to fumigants while handling cargo from shipping containers found that container handlers may have a greater risk of neuropsychological problems.⁹
- A 2014 study of ALS “hot spots” in northern New England examined whether water quality and a toxin produced by cyanobacteria were environmental triggers. It concluded broadly that poorer lake water quality was significantly associated with increased odds of being in an ALS cluster in the region.¹⁰

Regarding the last study, the petitioner noted that cyanobacteria is frequently found in New Zealand rivers and water systems.

Mr Barton also told us about Australian media news coverage of the work of Professor Dominic Rowe of Macquarie University. Professor Rowe has treated 889 MND patients, many from the New South Wales town of Griffith in the Murrumbidgee Irrigation Area. Mr Barton said researchers are investigating links to blue-green algae, pesticides, and heavy metals, and have found that people in Griffith are seven times more likely to develop MND.

Financial costs of MND

Mr Barton outlined the financial costs of supporting the growing incidence of MND in New Zealand. He said that, as most people diagnosed with MND are unable to work, people with

⁷ [A Temporal Association between Accumulated Petrol \(Gasoline\) Lead Emissions and Motor Neuron Disease in Australia - PMC.](#)

⁸ [Environmental and Occupational Risk Factors of Amyotrophic Lateral Sclerosis: A Population-Based Case-Control Study - PMC.](#)

⁹ [Neuropsychological symptoms in workers handling cargo from shipping containers and export logs - PubMed.](#)

¹⁰ [Mapping amyotrophic lateral sclerosis lake risk factors across northern New England - PubMed.](#)

MND rely on the Supported Living Payment from the Ministry of Social Development for basic living costs. Some MND patients may be entitled to Individualised Funding from the Ministry of Health, which is tailored to meet the individual needs of the person being supported, such as payment for a caregiver.

The petitioner told us that, as MND is a terminal illness with no cure, palliative care is the only assistance available to most patients. Palliative care can assist with physical symptoms and emotional stressors. He said that, as motor functions decline, MND patients will need equipment to help with things like moving and eating. He said this will vary from patient to patient. Mrs Barton's equipment had so far cost \$73,382. These costs included a powered wheelchair, house modifications, hospital bed, and gastronomy tube installation.

Mr Barton said MND is costing New Zealand a great deal of money. He believes investment is urgently needed to record and investigate the causes of MND in order to prevent further cases.

Comments from the Ministry of Health

The ministry acknowledged the effect that MND has on individuals and their whānau. It commended the petitioner for his efforts to improve the lives of people with MND. It acknowledged the research papers provided in the petitioner's submission linking MND with exposure to chemicals. The ministry told us it agrees that there is a need to gather information to identify the causes of MND.

The ministry does not support MND being made a notifiable disease. It told us that the aim of making a disease or a condition notifiable is to assist the surveillance, monitoring, and response of a disease that presents a risk to public health. Mostly it is infectious diseases that are made notifiable. The ministry told us that a notifiable disease requires follow up, such as contact tracing and other measures to control the spread of the disease.

We heard that the advantages of making a disease notifiable need to be balanced against the disadvantages. Disadvantages can include intrusion into the privacy of patients, and increased workload for health professionals.

We were told that at the time of our hearing the ministry was reviewing the criteria for making a disease or condition notifiable. It said that it was unlikely that MND would meet the criteria, as MND does not have the potential to cause outbreaks, and there are no definitive measures to prevent the disease. The ministry said it is hard to make a case that a public health response is required for each individual MND case. There can be a long period between the time that a person is exposed to factors which may cause MND and the development of symptoms.

The ministry believes that the need to collect information about MND would be better met by a registry than by making the disease notifiable. It said it is interested in working with the New Zealand MND Registry to see whether the registry could be improved to enable it to collect more information.

We were told that currently there is no legislative basis for requiring people diagnosed with MND to register on the New Zealand MND Registry. The ministry said it is interested in the "opt-out" option suggested by the petitioner, but told us that currently there is no mechanism

that could require that. It noted that the New Zealand Cancer Registry is a mandatory register, with no option for people diagnosed with cancer to “opt-out”. However, the ministry questioned whether a person diagnosed with MND who did not want to be on the register should be compelled to be on it.

We asked whether “public health research” could be added to the criteria for making a disease notifiable, as a way of recognising the value of gathering information for a condition such as MND. The ministry told us it was possible that this could be included in its review of criteria for making a disease or condition notifiable. However, it reiterated that the main purpose of making a disease or condition notifiable is to enable a public health response.

Our response to the petition

We thank Mr and Mrs Barton for their willingness to share their experience of MND with us. We saw clearly their commitment and loyalty to each other. We recognise that their petition aims to increase understanding of the disease in order to improve outcomes for other people.

We appreciate the petitioner’s advocacy to make MND a notifiable disease. However, we are not convinced that making MND notifiable would necessarily lead to an improvement in prevention, diagnosis, or treatment of the disease.

However, we are persuaded that there is a need for further research and for the collection of information that could help in understanding why New Zealand has such a high rate of MND. We appreciate that not every person who is diagnosed with MND may be ready or willing to share that news with others. We share the ministry’s reluctance to compel people at a very difficult time of their lives to register on the New Zealand MND Registry if they are not ready or willing to do so.

We welcome the comments from both the petitioner and the ministry that there is value in exploring whether the role of the New Zealand MND Registry could be expanded. We understand that this could enable the registry to collect more data, especially about the locations and occupations of people diagnosed with MND, as well as any other environmental factors.

The ministry expressed willingness to work with the registry. We recommend to the Government that the Ministry of Health work with the New Zealand MND Registry to enable the collection and analysis of occupational and environmental factors that potentially contribute to New Zealand’s high incidence of MND.

Appendix

Committee procedure

The petition was signed by 2,568 people. It was presented to the House by Dr Vanessa Weenink on 23 July 2024, and referred to us. We met between 26 September 2024 and 6 November 2025 to consider it. We received written and oral submissions from the petitioner and the Ministry of Health.

Committee members

Greg O'Connor (Chairperson)
Carl Bates (until 29 January 2025)
Kahurangi Carter (from 29 January 2025)
Greg Fleming
Paulo Garcia (from 29 January 2025)
Francisco Hernandez (until 29 January 2025)

Related resources

The documents we received as evidence in relation to this petition are available on [the Parliament website](#).

A recording of our [hearing with the petitioner on 12 December 2024](#) can be accessed online on the Parliament website.