New Zealand House of Representatives
Te Whare Māngai o Aotearoa

Petitions Committee
Komiti Whiriwhiri Take Petihana

54th Parliament
December 2024

Petition of Epilepsy Waikato Charitable Trust (EWCT): Fully fund the vagal nerve stimulator (VNS) for adults with intractable epilepsy

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

Contents

Petition of Epilepsy Waikato Charitable Trust

Recommendation

The Petitions Committee has considered the petition of Epilepsy Waikato Charitable Trust (EWCT)—Fully fund the vagal nerve stimulator (VNS) for adults with intractable epilepsy—and recommends that the House take note of its report.

Request for funding of vagal nerve stimulation devices

The petition was presented to the House on 26 July 2023. It requests:

> That the House of Representatives urge Whatu Ora Health New Zealand to fund vagal nerve stimulation (VNS) therapy for adults with intractable, medication-resistant epilepsy as an adjunct treatment.

The Petitions Committee of the 53rd Parliament began considering the petition. It received a submission from the petitioner, Epilepsy Waikato Charitable Trust (EWCT). We resumed consideration in the 54th Parliament and received written submissions from Epilepsy New Zealand, the Ministry of Health, and Pharmac. We heard oral evidence from the petitioner, Epilepsy New Zealand, the Ministry of Health, and Pharmac.

Comments from the petitioner

EWCT said that at least 50,000 New Zealanders live with epilepsy. This debilitating condition not only directly affects their health but also other parts of their lives, including their likelihood of having accidents, their ability to drive, and their mental health. The petitioner cited a 2018 survey by the Ministry of Health.[1] It recognised that many health professionals have little understanding of epilepsy, and the condition is not featured in reporting on burden of disease or long-term conditions.

EWCT said that conventional medications provide no seizure control for at least 30 percent of people with epilepsy.

Vagus nerve stimulators

The petitioner explained that the vagus nerve stimulator (VNS) is a small device implanted under the skin in the chest and connected to the vagus nerve in the neck. It delivers mild pulses to the brain through the vagus nerve, which can help to prevent seizures and to stop them if they start. The frequency and intensity of the pulses can be adjusted as needed.

Patients can sweep a magnet over the device to generate an extra dose if a seizure starts or they feel one coming on. This can prevent or shorten a seizure and reduce recovery time afterwards. The petitioner said that side effects are usually tolerable, but the VNS can be switched off or removed with no long-term consequences to the patient if needed.

[1] Ministry of Health, 2019, Epilepsy Consumer Experience Survey 2018.

EWCT cited studies from Australia, the USA, and Europe that showed reductions in seizures and shorter recovery times from patients using a VNS. Australian studies also showed a reduction in sudden death and an improvement in mood, which is important as depression and suicide attempts are high in people with intractable epilepsy. VNS devices have been used in Europe, the USA, and Australia since the mid-1990s.

Comments from Epilepsy New Zealand

Epilepsy New Zealand supported EWCT's petition. It told us that severe treatment-resistant epilepsy is a devastating condition and VNS is the only treatment that may work for patients with medication-resistant epilepsy. It also emphasised that meta-analyses conducted overseas showed significantly better odds for these patients when treated with VNS. It pointed out that VNS is already used for a small number of paediatric patients at Te Whatu Ora Auckland but there is no equivalent service available for young adults or adults.

Epilepsy New Zealand said it has made multiple submissions to various agencies trying to get funding for VNS. In 2017 it presented to the Northern Region Clinical Practice Committee. It told us the chair of that committee concluded in his report that it would be reasonable to run a pilot study of 30 patients and to monitor the effectiveness of VNS for these patients. However, funding to run this study was never provided.

Epilepsy New Zealand told us a small number of adult patients in New Zealand have had VNS implanted, through individual funding decisions made by ACC or public high-cost treatment funds. These patients have not become seizure-free but have seen a reduction in symptoms and an improvement in their quality of life.

Cost of vagus nerve stimulators

The petitioner said that implanting a VNS is a one-and-a-half-hour operation performed by a neurosurgeon. Units cost about $30,000, which does not include the medical costs of implantation. EWCT contrasted this to the economic burden of epilepsy, which includes medical costs, costs to carers, absenteeism, welfare, and premature mortality.

Epilepsy New Zealand estimated the cost of surgery and inpatient stay to be about $20,000, for a total of around $50,000. It said that, depending on use, the battery of an implanted VNS device will last between five and seven years. Once the battery runs out the unit needs to be replaced, but the leads connecting the unit to the nerves do not. Epilepsy New Zealand said this means the cost of the replacement device would be around $23,000, and the replacement surgery would also be shorter than the initial implantation.

Epilepsy Waikato Charitable Trust told us it is only aware of one company globally that makes VNS as an internal implant. Other companies produce external VNS devices. EWCT told us it has not considered external devices as these are not available in New Zealand. Epilepsy New Zealand said it does not consider there is evidence supporting the efficacy of external VNS devices.

Comments from Pharmac and the Ministry of Health

Pharmac told us that vagus nerve stimulators are classed as a medical device. Currently, Te Whatu Ora | Health New Zealand makes decisions about which medical devices are used in hospitals. However, Pharmac is working with Te Whatu Ora and suppliers towards a new way of managing medical devices, to be in place by 2025. Under the new system, Te Whatu Ora hospitals will only be able to purchase medical devices that are listed on a schedule managed by Pharmac.

Pharmac said that once this system is in place it will have application pathways for considering new technologies and changes to existing devices using the same funding criteria as medicines.[2] Funding applications will be assessed by technical experts alongside public consultation. Decisions will be made based on how the proposal for VNS devices compares to other proposals, the overall benefit they provide, and the funding available.

The Ministry of Health recognised that drug treatments do not work for everybody and that both clinicians and patients want to have as broad a range of options as possible. It acknowledged that international studies have shown the efficacy of VNS in treating medication-resistant seizures and that it is an approved therapy in Europe and the United States.

The ministry said it is aware some VNS devices are already being inserted, such as in the Auckland paediatric health setting. It acknowledged that this setting has a good multi-professional setup to assess where the devices can be best used. The ministry said there is currently unwarranted variation in the broader health system, and eliminating this is one of Te Whatu Ora's key aims.

The ministry says it supports Pharmac and Te Whatu Ora in their intended roles assessing medical devices. It recognises that this is a complicated decision that needs to consider not only the medical costs but also the cost to individuals and families of untreated epilepsy. It emphasised that the decision-making process needs to be transparent and evidence-based.

Our response to the petition

We thank the petitioner for raising the difficulties faced by those living with intractable epilepsy and the potential improvement that an additional treatment option like VNS would bring to their lives. We note that VNS is considered a valid treatment option internationally, and that some good results for some patients have been shown in the overseas research cited by the petitioner, Epilepsy New Zealand, and the Ministry of Health.

As noted by Pharmac and the Ministry of Health, the funding decisions for medical devices like VNS will lie with Pharmac. We note that Pharmac is setting up an application pathway for medical devices that will enable VNS to be assessed for funding. We respect Pharmac's independent funding process. We understand that, as part of this process, Pharmac will consider other competing devices and treatments. We do not believe it is Parliament's role to influence which medicines and devices should be funded.

[2] Pharmac's approach to health technology assessment can be found in the Prescription for Pharmacoeconomic analysis.

We encourage the petitioner to apply through Pharmac's funding pathway once it opens for applications. We recognise that epilepsy is a serious condition that has a major impact on people's lives, especially those who are not responsive to pharmaceutical treatment. We understand that the wait may be frustrating. We thank Epilepsy Waikato Charitable Trust for its work and ongoing advocacy for New Zealanders living with epilepsy. We wish EWCT all the best for any future applications for funding VNS treatment and for its other work.

Appendix

Committee procedure

The petition was referred to the Petitions Committee of the 53rd Parliament on 26 July 2023. It met on 3 August 2023 to consider it. The committee received a written submission from the petitioner.

On 6 December 2023, the petition was reinstated with the Petitions Committee of the 54th Parliament. We met between 27 June and 12 December 2024 to consider it. We received written submissions from Epilepsy New Zealand, the Ministry of Health, and Pharmac, and heard oral evidence from the petitioner, Epilepsy New Zealand, Pharmac, and the Ministry of Health.

Committee members

Greg O'Connor (Chairperson)
Carl Bates
Kahurangi Carter (to 8 May 2024)
Greg Fleming
Francisco Hernandez (from 8 May 2024)

Dr Vanessa Weenink participated in some of our work on this petition.

Related resources

The documents we received as evidence in relation to this petition are available on the Parliament website.

A recording of our hearings can be accessed online on the Parliament website.