

Forbidden Pharmacy

FORBIDDEN PHARMACY

Epilepsy New Zealand is proud to stand alongside 17 other patient organisations in support of the [Forbidden Pharmacy](#) – a powerful public awareness campaign highlighting the reality faced by thousands of New Zealanders who cannot access life-changing medicines that are already available in many other countries. The campaign calls on the Government and Pharmac to ensure New Zealanders living with epilepsy have access to the medicines they need to achieve the best possible health outcomes.

Specifically, we are advocating for:

- Public funding of [Fycompa® Perampanel](#) for eligible New Zealanders living with epilepsy.
- Access to a broader range of treatment options for people with hard-to-control seizures when existing funded medicines have not been effective.
- A reduction in the physical, emotional, and financial burden that uncontrolled seizures place on individuals, families, whānau, and the healthcare system.
- Equitable access to epilepsy medicines, regardless of where someone lives or their financial circumstances.

For many people living with epilepsy, Perampanel represents an important treatment option. However, because it is not publicly funded in New Zealand, eligible patients who wish to access it must currently pay significant out-of-pocket costs. For many individuals and families, this places an effective treatment beyond their financial reach.

By highlighting Perampanel through the Forbidden Pharmacy campaign, Epilepsy New Zealand aims to raise awareness of the real-life impact that limited access to funded medicines has on people living with epilepsy. Public funding would ensure that access to Perampanel is determined by clinical need rather than a person's ability to pay.

For people whose seizures remain uncontrolled despite trying other medicines, Perampanel can provide a vital additional treatment option. Improved access has the potential to reduce seizure frequency, improve safety and independence, enhance quality of life, and enable greater participation in education, employment, and community life.



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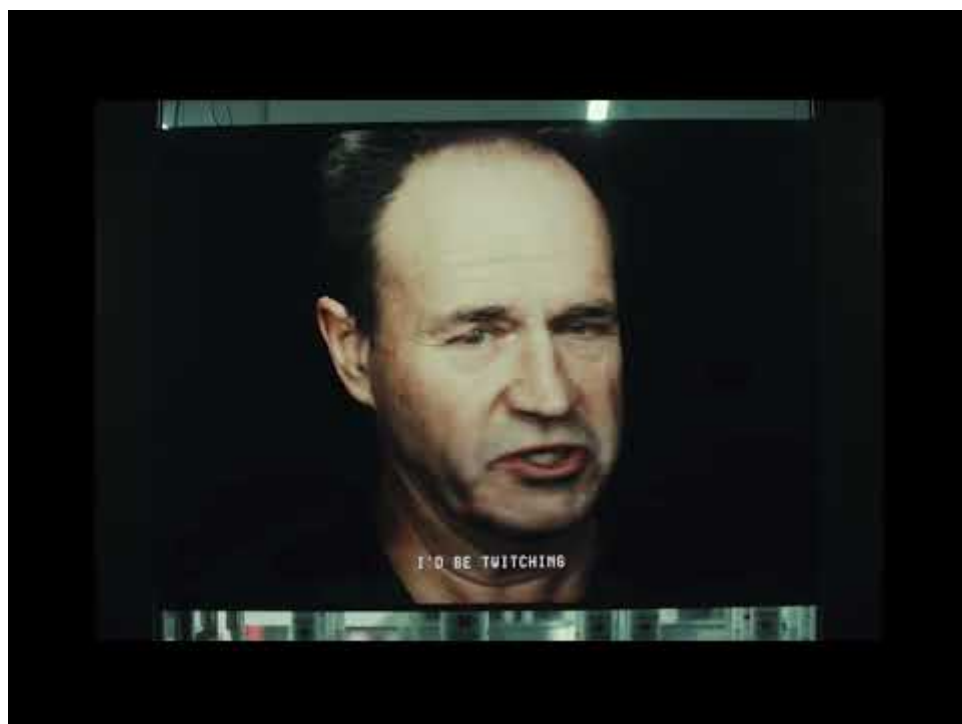


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HEAR FROM GLENN, CHAIR OF EPILEPSY NEW ZEALAND

In this short video, Glenn explains why Epilepsy New Zealand is part of the Forbidden Pharmacy campaign and why access to the medicines people with epilepsy need matters. He shares what the campaign is calling for and why change is needed to ensure people can access effective treatment.

Add your voice to the campaign. Sign the [open letter](#), show your support and help us call for better access to essential epilepsy medicines. Together, we can make sure people with epilepsy aren't left without the treatment they need.



FORBIDDEN PHARMACY – PRESENTING THE OPEN LETTER TO PARLIAMENT

On Tuesday 22 September 2026, 17 patient organisations, including Epilepsy New Zealand, came together at Parliament to present an open letter calling for greater access to medicines that remain unfunded, along with a long-term plan to improve medicine access in New Zealand.



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Despite the gloomy weather, our CEO, Tracy Tierney, joined the campaign alongside two long-standing supporters of Epilepsy New Zealand, David and Joy Thorp, to add their voices to the call for better access to medicines.

Representatives from all major political parties were on hand to receive the Open Letter, which has now gathered more than 10,000 signatures from New Zealanders supporting improved access to medicines.

Read more about the campaign in The Post's article published on 26 September [here](#).

The Open Letter remains open for signatures, and we encourage more New Zealanders to add their voices. You can sign the Open Letter [here](#)
https://www.forbiddenpharmacy.org/?utm_source=epilepsy_nz&utm_medium=website&utm_campaign=forbidden_pharmacy_26



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David and Joy Thorpe with ENZ CEO Tracy Tierney

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