



Epilepsy Waikato Charitable Trust (EWCT)

PO Box 633 Hamilton 3240

30 May 2021

To the Honorable Andrew Little, Minister of Health

**Re: The Health Ministry's lead on a review into how brand switches are managed on anti-seizure medications: to review communication strategies, establish clear obligations across the health sector, improve communication technology and systems, receive expert advice on serum level testing for patients undergoing a switch and look at international approaches to the therapeutic equivalence of different brands of drugs.**

Dear Andrew

Concerns were first expressed in September 2018 by EWCT about the proposed brand switching of the anti-seizure medication lamotrigine to the generic brand Logem (a series of letters on this topic is on our website <https://ewct.org.nz/lamotrogine-funding-switch-our-response-to-the-change/>). On behalf of the Trust Board of EWCT, I wrote to Lisa Williams, the director of operations of Pharmac, asking for a reversal of Pharmac's decision to switch medications used to support seizure control. However, that advice, along with that given by Medsafe and others, was willfully ignored. Three years later, people with epilepsy still feel vulnerable about Pharmac's possible decision to brand switch in the future (and without notification) ([https://ewct.org.nz/wp-content/uploads/2020/08/6.-Letter-to-Health-Committee\\_clonazepam\\_phenobarbitone\\_EWCT\\_12Aug2020.pdf](https://ewct.org.nz/wp-content/uploads/2020/08/6.-Letter-to-Health-Committee_clonazepam_phenobarbitone_EWCT_12Aug2020.pdf))

Back in 2013, the British National Health System (NHS) proposed to allow medical professionals to switch people living with epilepsy on to generic medications to curb the cost of branded medications. After the proposal was released, several notable epilepsy organisations in the UK heavily campaigned against the decision and the National Institute for Care and Health Excellence revised the epilepsy guidelines in prescribing medications. Later the Medicines and Healthcare Products Regulatory Agency (MHRA) issued further guidelines which aimed to inform the decisions of prescribers, pharmacists, and people with epilepsy in relation to switching medicines. The voice of the people living with epilepsy in the UK was heard and changes were made.

Here in New Zealand, in contrast, the voices of the people were ignored and six people possibly lost their lives because of the switch (Chief Coroner's report in May 2021), and over 2,000 people returned to their branded version of lamotrigine by applying to Pharmac for an exemption because of major problems with the impacts of the generic drug. This was not a case of the nocebo effect, which was mischievously

reported in the media, but a clear message that there were concerns and serious problems with the switch. Another problem was that many clients were not told about the switch. The key point is that the generic forms are **not** identical to the original brand, including dosage rates, despite the statements to the contrary made by Pharmac in attempting to justify their poorly-informed, head-in-the-sand decision. That the medications differ is evident in the form of the >2000 exemptions made by Pharmac, plus the six unexplained deaths that the Chief Coroner could not rule out as being caused by the switch.

Pharmac says that it will work with the Medical Council, the Pharmacy Council, and the Royal New Zealand College of General Practitioners to improve brand change information. Does that mean that those living with epilepsy will continue to be subjected to more brand changing in the future? If so, can we be assured that Pharmac will strictly follow the MHRA UK guidelines on anti-seizure medications (ASMs) to avoid future calamities?

Based on Pharmac's recalcitrant behavior regarding the advice it received from MHRA and many others, and the disastrous outcomes arising from its decision to switch from lamotrigine to Logem, and the ignominious admission by Pharmac in the Coroner's Court that many with epilepsy were not informed about the switch, I have my doubts that Pharmac staff have learnt their lesson. That assurance has to be clearly dictated by the Ministry of Health to avoid any future possibility of ASMs ever being targeted again by Pharmac to save money. Pharmac have repeatedly stated that funding and costs are their main drivers, and that mindset (which ignored the ruination of the lives of many people with epilepsy) seems to still be paramount, unfortunately.

[https://ewct.org.nz/wp-content/uploads/2020/08/5.-Letter-to-Health-Committee\\_EWCT\\_20-July-2020.pdf](https://ewct.org.nz/wp-content/uploads/2020/08/5.-Letter-to-Health-Committee_EWCT_20-July-2020.pdf)

The Ministry of Health's review of systems around brand switching is appreciated but will the Ministry of Health accept those findings and take responsibility for them? Pharmac is a crown entity with the primary aim of securing medicines at the best possible price, including sourcing generic brands which have the potential to differ in their therapeutic response even though they are defined as bioequivalent to branded medicines. As noted above, generic brands are demonstrably not identical.

The Ministry of Health is responsible for the healthcare of all New Zealanders including the approximately 50,000 New Zealanders living with epilepsy. This equates to about 1% of New Zealand's population which is not an inconsequential number of people, many of whom face ongoing issues around their epilepsy. Since Pharmac's aim is at odds with the Ministry of Health's it is therefore important that the Ministry of Health, not Pharmac, takes responsibility for the health and welfare of its citizens by leading the review and taking responsibility for it.

In 2018, The Ministry of Health conducted a survey entitled, "Living well with epilepsy" and reported its findings in the "Epilepsy Consumer Experience". The 'Epilepsy Technical Advisory Group' found that people living with epilepsy are likely to be high users of health and social services and with significant personal and social sector costs. With that knowledge, and with the effort taken by the MOH to undertake that survey, I would expect that there is a vested interest in ensuring that people living with epilepsy will not be subjected to unnecessary harm in the future especially by medication switching. If no heed is taken at all to the surveys and reviews done by the MOH, then it is no more than an academic exercise designed

to appease our epilepsy community, which is unforgiveable given that it is a legal and moral requirement of the MOH to look after all the citizens in New Zealand and especially those with disabilities.

Yours faithfully,

Maria Lowe (epilepsy advisor)

*On behalf of, and endorsed by, the Trust Board of Epilepsy Waikato Charitable Trust (EWCT)*

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**Note: EWCT ([www.ewct.org.nz](http://www.ewct.org.nz)) is a regional epilepsy provider not aligned with Epilepsy New Zealand**

cc. Hon Tim Macindoe, Patron EWCT

Dr Ashley Bloomfield, Director-General of Health

Dr Gaurav Sharma, MP for Hamilton West

Morag McDowell, Health and Disability Commissioner

Resources:

<https://ewct.org.nz/lamotrogine-funding-switch-our-response-to-the-change/>

<https://ewct.org.nz/living-challenges-epilepsy/>

<https://ewct.org.nz/we-are-removing-stigma-fear-and-prejudice-around-epilepsy/>

<https://ewct.org.nz/sudep/>

<https://ewct.org.nz/our-phone-chats/>