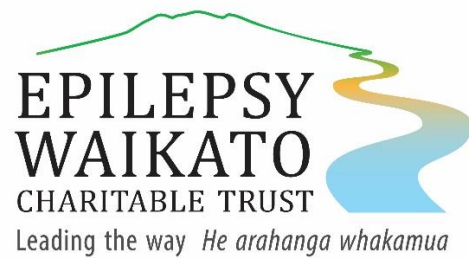


Epilepsy Waikato Charitable Trust (EWCT)
PO Box 633
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12 October 2019

To whom it may concern [PHARMAC]

Re: Petition of Sarah Teare for Patient Voice Aotearoa: Publicly continue to fund Lamictal for epilepsy and mental health patients

On the 1st of October 2019, Pharmac ceased funding the antiepileptic branded drug Lamictal/Lamotrigine for the generic form Logem despite warnings from Medsafe NZ and others. Lamotrigine is considered a category 2 medication in the UK, which means that the prescriber would need to judge each individual when deciding whether or not to switch between different versions of a medicine whilst considering a person's treatment history and seizure frequency as well as their thoughts and concerns. In contrast, Pharmac's director, Lisa Williams, stated to the New Zealand prescriber, "We know change can be difficult for some people but clinical experts have told us people shouldn't notice a difference when changing to Logem." Her comment showed a lack of empathy for people living with epilepsy, a clear disregard for its complexities, and a lack of understanding of the condition and its impacts.

For a person living with epilepsy it can take months, or even years, to find the right medication that controls seizures. Once that medication is found then a person will hold onto it tightly through fear of having another seizure. As one young client recently said, "I know what a seizure feels like. I didn't like it and I don't want it to happen again. If it does, then I will lose my driver's licence, my job and my future." That is a substantial personal fear and, unfortunately, it is a reality for many who will face break-through seizures as a result of this medication change. For this young man, he is prepared to pay privately for his lamotrigine medication, a cost that may become prohibitive over time. Such an option (paying privately) is not viable for many people with epilepsy.

There are many burdens to having epilepsy, and a loss of a driver's licence is only one of them. Disturbingly, the NZTA stance towards this brand switch of medication has changed within the past six months. Previously, "NZTA noted a brand change does not constitute a treatment change for purposes of driving and considered that any risk from changing would be extremely low." (11/4/2019). Now, however, "NZTA recommends that patients consider voluntarily avoiding driving for eight weeks. If a patient has a seizure within the first eight weeks of a medicine brand change, application can be made to NZTA for consideration of a six-month stand down period instead of the standard 12 months." (30/9/2019). For many it would be tempting not to disclose any seizure out of fear of losing a driver's licence and with it independence and a potential loss of livelihood.

Other burdens to having seizures involve the human cost. These include possibilities of hospitalisation, absenteeism from school or work, the loss of a job, and financial stress. To these can be added the unreported conditions of social anxiety and depression and the slight (but

nevertheless real) possibility of SUDEP (Sudden Unexpected Death by Epilepsy). All of these potential burdens affect the quality of life of a person living directly, and also others (such as family and friends) living indirectly with epilepsy. Therefore the stress of a state-sanctioned medication change only adds to the unpredictability and precariousness of their lives.

According to the International League Against Epilepsy (ILEA), the overall rate of people with epilepsy experiencing a mood disorder stands at 25–50% higher than that of the general population. Our mental health system does not appear to respond favourably to people with epilepsy, and for those who are experiencing higher levels of anxiety and depression, there is an appalling suicide rate in this country. Another report from Denmark suggests that people with epilepsy have triple the risk of attempting suicide and at least double the risk of death by suicide, compared with the risk for the general population. To jeopardise a person's mental health to "free up more than \$30 million over the next five years" is very short-sighted. And to pit one group of people against another with this statement, "All this money saved will be used to fund other medicines for New Zealanders," is callous in that many people using Lamictal for epilepsy or mental health – two serious medical conditions – are in effect being regarded as of secondary importance in our society and that their burdens are of little consequence.

I have taken great pains to remain neutral about the brand switch whilst giving my clients as much information that they needed to ensure that any worries are not inflated needlessly. However, a number of my clients have reported back to me with concerns and deteriorations in their seizure control. They are experiencing break-through seizures, which in some cases have intensified, side effects with the new drug Logem have become intolerable, and they are anxious and depressed. These results are not the much-publicised 'nocebo affect' (discussed in the media recently) but a stark reality resulting from Pharmac's unfortunate experiment.

I appreciate that Pharmac has a difficult task in getting value for money, and for wanting to fund medications for many other needy people, but to choose a particularly vulnerable group of people, who have a difficult time as it is with epilepsy and its innumerable impacts, to save money beggars belief. Epilepsy is the most complex neurological condition there is. Most people are able to find seizure control with medications, but choosing the right ones can take time. If Lamotrigine/Lamictal is the only medication that works then to have to have a trial period of a brand switch to see if a generic brand works, is heartless and potentially expensive in financial and other terms. Moreover, it would seem to be contrary to basic human rights in that a group of people with a disability, namely epilepsy (also those with a mental health condition), is being treated unfairly and less favourably than other people because of the disability. Some people with 'brittle' epilepsy will react strongly to small differences found between medications, despite Pharmac's disingenuous reassurance that people will not experience any, and these same people will battle again for seizure control, which may take years to be restored.

I and the Trust Board of Epilepsy Waikato Charitable Trust (EWCT) strongly agree with Sarah Teare's petition that Lamotrigine/Lamictal be funded for those ~10,000 New Zealanders struggling for a quality of life that is only found on this medication. Not to do so contravenes the doctor's Hippocratic oath, which is to "do no harm", our Disability Code of Rights, the Human Rights Act, and the 'Best Practice' code as used by UK's MHRA (Medical and Healthcare Products Regulatory Agency). Nor does it honour the Treaty of Waitangi (1840). A quality of life for 10,000 people in New Zealand is worth defending.

In the meantime, the University of Auckland will collect data from those who are experiencing problems with this lamotrigine brand switch, but a good number of people with epilepsy, who do not own a computer and are not computer literate, will not be part of that data collection. It would therefore be pertinent for Pharmac to read and digest the Ministry of Health's "Living well with epilepsy" document (Feb 2019) to see how poorly people are doing generally in New Zealand. Here are some noted facts to consider.

- 1) Epilepsy is a hidden burden for people living with this condition. It has a low profile within the health system, does not feature in long-term conditions or 'burden of disease' reporting and many people (including health professionals) have little or no understanding of how epilepsy affects people.
- 2) In addition to the social impacts of epilepsy, people with epilepsy are also likely to be high users of health services, regularly accessing hospital services for emergency care, outpatient neurology or paediatric appointments, diagnostic tests, diet therapy, speech and occupations therapy, physiotherapy and neuropsychology support.
- 3) The majority of people with epilepsy accessing inpatient care have unplanned admissions and 22% of these people will have multiple admissions.
- 4) Between 2013 and 2017 there were 124 deaths with epilepsy recorded as the cause of death. In 55% of these cases, the cause of death was reported to be SUDEP.
- 5) Antiepileptic medication is not without challenges for many people. There can be distressing side effects, particularly lethargy or depression. In some cases, it takes years and any change in medication can result in an increase in seizures.
- 6) Hospital data information shows that the rate of epilepsy related hospital admissions for Māori is one and a half times that of non-Māori. Māori are more than twice as likely to have four or more admissions within a year.

In other words, the health system is not geared up to help people with epilepsy and a brand switch just complicates and aggravates the situation further for many.

Yours faithfully,

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On behalf of

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Note: EWCT (www.ewct.org.nz) is a regional epilepsy provider not associated with Epilepsy New Zealand