



Epilepsy Waikato Charitable Trust (EWCT)
PO Box 633
Hamilton 3240
31 July 2020

To the members of the Health Select Committee

Re: Pharmac to follow, and understand, UK's MHRA guidelines on anti-epilepsy medication for AEDs in New Zealand

Thank you for your positive response to Sarah Teare's petition, "That the House of Representatives urge Pharmac to continue funding Lamictal for epilepsy and mental health patients." That petition was heard on July 22nd 2020.

Our epilepsy community now has to be assured that Pharmac will strictly follow the MHRA UK guidelines on anti-epilepsy drugs (AEDS). That assurance has to be clearly dictated by the Ministry of Health to avoid any future possibility of AEDs ever being targeted again by Pharmac to save money. I urge the ministers in the Health Select Committee to strongly support the Ministry of Health's role in outlining what the terms and conditions are for Pharmac with regard to AEDs. Pharmac is a Crown entity, and is answerable to the Minister of Health, not the other way around.

Epilepsy is a complex neurological condition requiring skill by a neurologist/paediatrician in the treatment of seizures. Unfortunately, there isn't a single medication that works for all people living with epilepsy and it can take years to find the right AED that is going to work. This was recognised by the Medicines and Healthcare products Regulatory Authority (MHRA- UK), which issued new guidelines in 2014 on prescribing AEDs to those living with epilepsy. This gold standard in the medication treatment of our people was disregarded by Pharmac when sourcing information on whether or not the medication switch from lamotrigine to logem was going to be safe. Indeed, it was demonstrably not safe for many of the 10,000 New Zealanders who were forced to make that switch. The Ministry of Health must now ensure that MHRA's guidelines are followed by Pharmac when sourcing AED medications in the future. The needs of our clients are paramount. Our (EWCT) stance has always been that our clients stay on the medications that they were prescribed. To switch to another AED would potentially undo the hard work in gaining seizure control whilst recognising the risk to enduring break-through seizures, and SUDEP (Sudden Unexpected Death by Epilepsy). The human cost is high.

The MHRA guidance divides AEDs into three categories according to the importance of maintaining a consistent supply and depending on whether there is considered to be a risk of problems if switching between different versions.

Category 1 Phenytoin, carbamazepine, phenobarbital and primidone. Specific measures are necessary to ensure consistent supply of a particular product. **This means that individuals should not be switched between versions of these AEDs, but should always kept on the same version.**

Category 2 Sodium valproate, lamotrigine, perampanel, retigabine, rufinamide, clobazam, clonazepam, oxcarbazepine, eslicarbazepine acetate, topiramate and zonisamide. The need for continued supply of a particular product should be based on 'clinical judgement' (the doctors judgement of the risk of problems) and in consultation with the individual. **This means that a doctor should decide, with the individual, whether it is important to always stay on the same version or whether it is OK to switch between different versions.**

Category 3 Levetiracetam, lacosamide, tiagabine, gabapentin, pregabalin, ethosuximide and vigabatrin. No specific measures are normally required and these AEDs can be prescribed generically. **This means that individuals can be switched between different versions of their AEDs.**

<https://www.epilepsysociety.org.uk/mhra-guidance-anti-epileptic-drugs#.XyHuc4gzblU>

It has taken years of research to understand the implications involved in medication switching.

It is therefore imperative that New Zealanders living with epilepsy have the support of the Ministry of Health in making sure that there will be no threat of brand switching in the future by Pharmac.

Yours faithfully,

Maria Lowe (epilepsy advisor)

On behalf of Epilepsy Waikato Charitable Trust (EWCT)

maria@ewct.org.nz

021 888 293

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