



Epilepsy Waikato Charitable Trust (EWCT)
PO Box 633
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12 August 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 when tendering for medicines

It has just been brought to our attention that once again Pharmac is looking at tendering two anti-epilepsy medications (clonazepam and phenobarbitone) despite the outrage by the epilepsy and mental health communities, and clients, over the recent lamotrigine/logem debacle. Phenobarbitone is a category 1 medication, using the MHRA (UK) guidelines, which means that people taking this medication should not be switched between versions of the same drug. Clonazepam is regarded as a category 2 medicine, which means that a doctor should decide, with the individual, whether it is important to always stay on the same version or whether it is okay to switch between different versions.

The MHRA guidelines are very clear and are designed to keep people living with epilepsy safe from harm since these medications are designed to pass the blood brain barrier to effect control on seizures. They are heavy duty medications with a list of potential side effects. Extreme care, attention and skill are used by neurologists and paediatricians in selecting the right medications for the types of seizures present.

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

There is no magic pill that works for all people living with epilepsy and so begins the journey in finding the right medication (AEDs) that calms the over-excited neurons which produce seizures. Becoming seizure-free becomes an important part of living well with epilepsy and it can take years of heartache, frustration, fear, anxiety and depression to find a treatment option that works. For seventy percent of people it is the medications that they take which gives them a quality of life which is not possible by other means. Why, then, would Pharmac believe that tendering for really important anti-epilepsy medications (AEDs) would be of little effect to the people who use them (especially as the detrimental outcomes, including potentially a number of deaths, of the lamotrigine/logem switch have been well documented)? There are approximately 50,000 New Zealanders living with epilepsy representing at least 1% of our population. They do deserve to be treated fairly.

There has been wide publicity regarding the lamotrigine/logem brand switch since October 1st 2019. Eight people have died possibly because of that switch. Hundreds of others (2418) have certainly

experienced a negative reaction and have endured break-through seizures or unpalatable side effects. These are not inconsequential happenings. For the people concerned there is a sense of vulnerability and of not being heard.

We implore you to please strongly suggest to the Ministry of Health that they enact the MHRA (UK) guidelines for AEDs immediately. Pharmac must be told to adhere to those guidelines and avoid targeting AEDS for tender in the future.

Thank you for your time.

Yours faithfully,

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