

**EPILEPSY ASSOCIATION OF NEW ZEALAND INC.**

6 Vialou St.,  
PO Box 1074  
Hamilton 3240, New Zealand

Tel: (07) 834 3556  
Email: [national@epilepsy.org.nz](mailto:national@epilepsy.org.nz)  
Website: [www.epilepsy.org.nz](http://www.epilepsy.org.nz)  
Registered Charity: CC10611



**EPILEPSY NEW ZEALAND®**  
THE NATIONAL EPILEPSY ASSOCIATION OF NEW ZEALAND  
*kia titiro ki te tangata - see the person*

26th September 2018

Pharmac  
PO Box 10254  
WELLINGTON

Email: [procurement@pharmac.govt.nz](mailto:procurement@pharmac.govt.nz)

**Submission and Proposal to fund sole supply of Lamotrigine.**

Epilepsy Association of New Zealand Inc (Epilepsy New Zealand) appreciates the opportunity to comment on the proposal for Pharmac to move to a one funded brand of Lamotrigine (Logem).

Epilepsy New Zealand is committed to supporting people living with epilepsy so as to positively influence their quality of life.

Notwithstanding comments here, Epilepsy New Zealand may make further comment as the proposal progresses.

**Summary**

Epilepsy New Zealand does not support the proposal to reduce from three funded brands to just one funded brand from 1st May 2019.

Our concern is that:

1. The risk to safety of people living with epilepsy in changing brands
2. The support of people living with epilepsy is insufficient during this proposed transition.
3. A lack of confidence and trust exists with Pharmac brand change based on past performance e.g. Efexor –XR to Enalafox-XR.
4. The cost savings expected at DHB level benefiting other than epilepsy health outcomes.

Epilepsy New Zealand believes the proposal is not in the interests of people who are currently free from seizures. Epilepsy New Zealand urges Pharmac to take further consideration of safety risks, support of those people involved and reinvestment into treatment and care of people living with epilepsy.

**Epilepsy New Zealand**

Epilepsy New Zealand is a non-profit voluntary membership incorporated society and registered New Zealand charity. We are the New Zealand Chapter of International Bureau of Epilepsy (IBE). We

represent a diverse membership of people living with epilepsy, their families, workplaces and community organisations.

We promote the interests of people living with epilepsy in order to positively influence the quality of life that they lead.

We accomplish our aims through practical, face to face delivery of educational services by our 15 professional educators located in our 12 offices throughout the country.

### **Living with Epilepsy**

We estimate that there are 48,000 people in New Zealand living with epilepsy and that around six people a day will be diagnosed with epilepsy. We know at least 40 people a year will die from SUDEP (Sudden Unexplained Death from Epilepsy).

We know that 70% of people diagnosed with epilepsy will have their seizures controlled by medication.

We know that living with epilepsy creates risk of social isolation, anxiety, depression, injury, suicide and death.

Experiencing a single seizure can be devastating resulting in loss of drivers' licences, often difficulties with employment and, as a result of not being eligible for disability allowance leaving them vulnerable and able to easily enter the poverty trap.

In many cases, people living with epilepsy have social interaction problems due to isolation that they experience and lack of education. People with epilepsy are often vulnerable whether their seizures are controlled or not.

### **Safety Risk**

Epilepsy New Zealand is aware that switching brands of antiepileptic medications carries risk as:

1. Recurrence of seizures in controlled epilepsy.
2. Seizure exacerbations.
3. Tolerability problems/side effects.

The medical advisory board noted that general batch variability exists. It also considered "in general, controlled trial did not suggest ... effect on seizures frequency; however, some of the small non-experimental cohort studies reported high switch back rates ..." These two comments from the advisory board alone means that Pharmac expects people to experience seizures because of this proposal. The GSK submission quantifies this at around 2,500 people.

Epilepsy New Zealand questions the advisory committee citing Lessing et al (2014) investigation study reporting no health outcomes measures associated with switching. Epilepsy New Zealand is a member of the Technical Advisory Improvement Services Group. This Group has the full support of the MOH data collection and yet struggles to find data in which it can be confident in relation to epilepsy outcomes. This in itself raised doubts over such measurement.

The effect of having a seizure on a person is devastating. This proposal places people who have total seizure control at risk of:

1. Loss of driving Licence.

2. Employment at risk either through lost time or loss of employment.
3. Possible WINZ assistance - People with Epilepsy are not entitled to Disability Support.
4. Mental Health Issues – level of confidence, anxiety, unpredictable psychological issues.
5. Burden on health system, individual health burden costs – Doctor visits, hospital admission, injury.
6. Level of independence.
7. Education and learning.
8. Effects on family, relationships etc.
9. Death through SUDEP, or accident such as drowning.

GSK claim that 10,000 people are affected by this proposal and that there is a 25% switch back rate. That means, as a minimum, 2,500 people are being put at risk.

Epilepsy New Zealand find that these risks to the individual are unacceptable.

### **Support of People with Epilepsy during Proposed Change**

Pharmac are forcing people living with epilepsy to transition drugs and therefore incurring Doctor consultation costs.

Expectation is that 25% of people during this exercise will experience a seizure placing them in harm's way and at risk including death. Pharmac provides no assistance in relation to costs incurred.

Whilst the medical advisory suggest pharmacies and GPs are important in providing support and reassurance around brand change they consider the most important factor in maintaining epilepsy control is medication adherence – Pharmac provide financial assistance to HCP's yet none for the 'patient'.

Named patient Pharmaceutical Assessment guidelines have not been offered by Pharmac or guidance provided. No pathway is provided other than user pays for those required to switchback.

Epilepsy New Zealand urges Pharmac to look beyond the numbers and to take a humanitarian and holistic viewpoint to support the people it will harm from its decisions.

### **Pharmac Lack of Trust**

Pharmac do not have a successful background in drug change.

Those that have experienced change before with Efexor –XR to Enalafox –XR have had confidence dashed by Pharmac. These people went through “a nightmare” and have been left feeling abandoned by Pharmac through misinformation, awareness, errors in dispensing and lack of engagement.

### **DHB Savings**

It would appear from the proposal that Pharmac consider this change will provide major cost saving at DHB level. It recommends that the savings be reinvested in new pharmaceutical funding to provide improved health outcomes for New Zealanders.

Considering the risk that Pharmac is placing upon people with epilepsy, Epilepsy New Zealand considers that theses savings be reinvested into improved epilepsy health outcomes for New Zealanders.

We do not have any objections to our submission being published. We would welcome the opportunity to discuss this submission.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'G. Ambler', with a horizontal line underneath.

Graeme Ambler  
**CEO/Secretary**  
**EPILEPSY ASSOCIATION OF NEW ZEALAND INC.**

*Mob: (022) 080 0105*

*Email: ceo@epilepsy.org.nz*