



26 April 2017

Health, Communities, Disability Services &  
Domestic & Family Violence Prevention Committee

Parliament House  
George Street  
BRISBANE QLD 4000

Dear Committee Members,

**RE: Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee consideration of the Public Health (Medicinal Cannabis Affordability) Amendment Act 2017**

I am writing in my role as CEO of Epilepsy Action Australia, a national non-profit organisation supporting people living with epilepsy and their families.

The issue of cannabinoid based therapies for the treatment of epilepsy has been a contentious issue between government bodies and consumer movements. A tension exists between those who are currently using unregulated or artisan cannabinoid based therapies for the treatment of epilepsy and existing state laws and regulations.

Two issues are prominent in the advocacy work we do with individuals and families, firstly the lack of availability of regulated bio-equivalent cannabinoid based therapies both in Australia and internationally; and secondly if a suitable regulated cannabinoid based therapy has been identified, the cost of the medicine is well beyond the financial means of most Queenslanders and fellow Australians, thus the need for affordable access to bio-equivalent cannabinoid therapies.

We have a number of Queensland families in the unenviable situation of having to rely on unregulated cannabinoid therapies supplied by either compassionate medicinal cannabis suppliers, often at no cost, or sourcing cannabis from the recreational black market. Some of these families (who would be willing to meet with you) have expressed the desire to transition themselves or their child to a regulated product despite the risk of increased seizure activity during this period of change. The benefits of utilising a regulated product reach beyond the medicinal benefits. Quality of life for the individual and their families will be improved when: they no longer need to constantly worry about police raids and confiscation of the unregulated cannabinoid based therapy they are dependent upon for management of their or their child's epilepsy; they no longer fear a visit by child services and the threat of having their child removed from their care; their child can attend school for a full day rather than being removed from school grounds for the midday dosing; they can openly administer cannabinoid based therapies during hospital admissions whilst it is monitored and charted by treating doctors without threats by hospital staff of calling police or removing the parent from the hospital grounds despite the severity of the child's condition or the fact that the cannabinoid based therapy has been witnessed to be an effective treatment in minimising seizure activity when conventional medications have failed.



Some families have attempted to access cannabinoid based therapies through the TGA SAS Cat B process only to find that they cannot afford the ongoing cost of the product. It has been confirmed by Tilray, a Canadian supplier of pharmaceutical grade medicinal cannabis with importation rights, that the average cost of medicinal cannabis for a child per day is more than AD\$90 and over AD\$200 for an adult. This is out of reach of most Australians and has the effect of driving patients to the unregulated market. Thus the need for affordable access to cannabinoid based therapies.

In the Public Health (Medicinal Cannabis Affordability) Amendment Act 2017 some terms require further clarification:

**Affordability** – who determines the definition of affordability? What base is this definition going to be measured from, will it be the average Australian income or the average welfare payment? Many of our clients with intractable epilepsy, or their families fulfilling the role of Carers, are recipients of welfare payments. Affordability is subjective depending upon the individual's context.

**Medicinal Cannabis** – it is suggested that 'full spectrum' be substituted in place of 'whole plant' as a more accurate reflection of the intended usage of the term.

There is contention between a multitude of competing interests about the use of organically grown, non GMO, full spectrum or single compound extracts versus pharmaceutical produced synthetic cannabinoid therapies. I believe a wide variety of cannabinoid based therapeutic products need to be made available in all forms. It is the collaborative decision making between the patient and doctor to determine the best product for the individual clinical situation, their philosophical positions and identified needs.

Epilepsy Action Australia supports Mr Steve Dickson MP's request of the Queensland Government to ensure *affordable* access to medicinal cannabis is made available in Queensland to patients now while a local industry under the Commonwealth licensing scheme further matures and local products are made available.

Thank you for the opportunity to contribute to this discussion as an advocate and representative of our Queensland clients living with epilepsy and their families.

Kind Regards



Carol Ireland

CEO Epilepsy Action Australia