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Committee Secretary
Senate Legal & Constitutional Affairs Committee
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Canberra ACT 2600

SUBMISSION TO THE SENATE LEGAL & CONSTITUTIONAL AFFAIRS COMMITTEE REVIEW OF THE
REGULATOR OF MEDICINAL CANNABIS ACT 2014

Introduction

Epilepsy Action Australia, established in 1952, is Australia's national provider of education and support services for people with epilepsy, their families, professionals and the community. Being driven by our vision of "optimal living for people with epilepsy", Epilepsy Action Australia delivers innovative, high quality services across Australia that increase epilepsy awareness, understanding, knowledge and skills to assist people with epilepsy to optimise their life outcomes.

Background

The severity and frequency of seizure activity varies widely in people living with epilepsy. Approximately seventy percent of people diagnosed with epilepsy have their seizures well controlled on the first or second anti-epileptic medication they try. The remaining thirty percent, unfortunately, continue to experience seizure activity despite trying numerous combinations of currently available anti epileptic medications. They are considered to have *intractable* (medication resistant) epilepsy. Of this group, some are diagnosed with catastrophic types of *epilepsy*, where they suffer recurrent severe and damaging seizures on a daily basis. This is a devastating fact of life for many families in Australia where tragically death, before the child reaches adulthood, could be the outcome.

However new hope has been given to these families from the positive results of early research and clinical case studies of treatment options that can significantly reduce the severity and frequency of seizures. The treatments are derivatives of cannabidiol from the cannabis plant.

Epilepsy Action Australia understands the legal issues in Australia: that cannabis cultivation and use is not legal in any Australian jurisdictions for any purpose, even though the international drug treaties to which we are party permit the medical and scientific use of drugs whose recreational use is prohibited.

We understand from social media and other sources that a number of consumers (parents) in Australia are gaining access to cannabis derivatives to treat seizures in the form of tinctures and oils. Given the catastrophic and debilitating nature of their children's epilepsy conditions it is not difficult to understand their desperation. These parents report immense improvement in the severity and frequency of their children's seizures and overall quality of life. Concern has been expressed that these consumers are using home-grown and 'black market' cannabis of uncertain medicinal quality, and that these desperate parents are also breaking Australian laws.

Epilepsy Action Australia supports any activity that expedites the provision of a national framework for the legal access to medicinal cannabis products for research and medicinal use whilst protecting individuals involved in the cultivation, manufacture, distribution, prescription, supply and administration of these product from prosecution and threat by government authorities to remove children from the care of their families.

Focus of this submission

In this submission we draw your attention to issues that may emerge as the *Regulator of Medicinal Cannabis Act 2014* is implemented in the future.

Issues:

Authorised Patient and Carers Scheme

Division 4, 19.4 (p.13) states that authorised patients and authorised carers are protected from *Narcotic Drugs Act 1967* and the *Therapeutic Goods Act 1989*. Is this protection extended to authorised persons carrying regulated medicinal cannabis products whilst transiting through or temporarily visiting Australian states and territories not party to the Act?

Importing and Exporting Licensing Scheme

Will authorised patients and authorised carers require an importing and exporting license to secure supplies of specific formulations of medicinal cannabis products not currently available in Australia for the treatment of rare and unusual health conditions?

Has the need for a special access scheme, similar to the existing Therapeutic Goods Special Access Scheme for unapproved or unavailable products, been considered when small quantities of highly specialised products are required as opposed to large corporations importing and exporting these products?

If an importing and exporting licence is required in this situation, is it reasonable that individual names on the Register of Import and Export Licences (point 7.26.b., p.19) be made public with potential risk to an individual's safety and security?

Will authorised patients and authorised carers be required to hold an importing and exporting license to carry reasonable quantities of medicinal cannabis products when travelling to or from international destinations whilst seeking medical treatment, visit family or holidaying? Will the protection, stated in point 4.19.4. (p.13), be extended to cover this situation? Will there be an avenue to request international co-operation and protection from prosecution in international jurisdictions in this instance?

Summary

Epilepsy Action Australia strongly supports this initiative, offering hope to hundreds of families living with the everyday reality of intractable and catastrophic epilepsies. For many of our families time is of the essence, with children failing to progress or even regression of their cognitive function and skills. The longer they have to wait to legally access medicinal cannabis products to manage their child's seizures the worse will be the outcome.

We welcome the establishment of a national framework and Regulator of Medicinal Cannabis and look forward to contributing to the ongoing development of the underlying policies, procedures and educational materials relevant to our consumer base.