

12 March 2015

Committee Secretary  
Senate Legal and Constitutional Affairs Committee  
PO BOX 6100  
Parliament House  
Canberra ACT 2600

RE: The Regulator of Medicinal Cannabis Bill 2014

Dear Committee Members,

I am writing with regard to the Regulator of Medicinal Cannabis Bill 2014, to state my support for the introduction and implementation of the Bill.

### Personal Background

I am the mother to two children, one of which is an 8yo boy with uncontrolled epilepsy. His epilepsy is a result of a botched birth involving a suction cup delivery. This caused a bleed on his brain, which caused Hydrocephalus, which meant he had his first brain surgery at 4 months old to insert a shunt. At 13 months, the shunt got infected, which led to Meningitis and Ventriculitis which caused a lot of damage.

His current labels are Hydrocephalus, Cerebral Palsy, Cortical Vision Impairment, Intellectual Impairment, and Epilepsy.

Out of all of these conditions, Epilepsy is the greatest challenge. It affects every part of our family life. Where, when and what we can do, as a family. My husband and I have separate holidays as we are too scared to travel long distances with our son, due to the unpredictability of seizures.

Our son has been sleeping either in our bed, or on a mattress on the floor next to our bed, for the last 3 years. This is due to the dangers of any nocturnal seizure going undetected, and the risk of associated death.

But it is not only the actual seizures that take their toll on my son and the family. It is the anxiety of waiting and watching for a seizure, it is the side-effects of the pharmaceutical medications - which include behavioural, physical, emotional, cognitive and psychological challenges. It is the doctors appointments, it is ensuring that anyone who is to care for my son is suitably qualified to deal with seizures - including family and friends, it is constantly considering whether we are doing the right thing for my son, especially in regard to pharmaceutical drugs, are they doing more harm than good? – it is EXHAUSTING!

My son has tried 9 different anti epileptic drugs, including the 2 he is currently on. It is a fact that once someone has tried 3 (some say 2) anti-epileptic drugs and they have not been effective, they are said to

have uncontrolled or refractory epilepsy, which means they are unlikely to become seizure free with the conventional drugs currently legally available.

[http://www.ilae.org/visitors/Documents/Epigraph\\_definitionofdrugresistantepilepsy.pdf](http://www.ilae.org/visitors/Documents/Epigraph_definitionofdrugresistantepilepsy.pdf)

<http://www.uptodate.com/contents/evaluation-and-management-of-drug-resistant-epilepsy>

The latest twist that Epilepsy has thrown at us is his recent diagnosis of ESES - Electrical Status Epilepticus of Sleep which means he is having continuous brain activity, or seizures, when he is asleep. Thus far the treatment has been increasing two of his anti-epileptic medications to an adult plus dose, trying to introduce another drug (which failed due to unacceptable side-effects) and weaning and removing one his medications which is known to aggravate ESES.

The next step the doctors want us to take is to introduce a steroid to his treatment plan. I have never heard a good report from any other family about using steroids. The common theme I hear is – it was the worst thing we ever did. I don't want to do it.

#### Personal requests regarding Medicinal Cannabis

I want to be able to legally access Medical Cannabis for my son. I want to have the choice to either grow my own plants, or to have access to a reputable grower who has the expertise required to produce the best quality plant product to be the basis of my son's medicine.

I want the choice to be able to prepare/produce my sons cannabis product myself, or to have access to a reputable manufacturer who would prepare my sons cannabis product to the highest possible standard.

I also seek assurance that there will be measures put in place to help ensure a continuous supply of the quality and quantity of cannabis that may be required to meet the demand of those who need it. This is one of a parents greatest fears, to find something that works for their child, but to then not be able to access it.

#### Response to Regulator of Medical Cannabis Bill 2014

I list my response to a number of points with direct reference to the Bill as follows:

##### [Clause 7 – provides for the Bill to apply only in participating States and Territories.](#)

My fear is that my State will not become a participating State. And if it doesn't, this would create a situation of medical refugees who are moving to those States who have become participants. Will there be an incentive for States to participate, or an assurance that the process of becoming a participant is made as simple as possible to encourage State participation?

##### [Division 3 – Medicinal Cannabis Licensing Scheme](#)

- I fully support measures taken to prevent diversion of medical cannabis to the illicit market, and especially to prevent the abuse and misuse of cannabis by minors.
- I would like to highlight the point here that there can be large differences in the quantity of cannabis required between patients, dependant on their diagnosis and treatment plan, which

needs to be considered during any licensing process. For example a pain management patient may need access to a lot less cannabis product than a cancer patient who is fighting their disease.

- I would also like to highlight the point that when defining allowable quantities of cannabis for medical purposes, only the dried mature processed flowers or buds of the female cannabis plant should be considered. Male plants, seeds, leaf, stalks and roots are of little consequence medically speaking.

#### Division 4 – Authorised patients and carers scheme

I want to highlight the fact that many possible users of medicinal cannabis would like to be able to go to their doctor/specialist to discuss such issues as:

- dosing, ie how to start taking cannabis products, how to find the optimal dose
  - interaction, ie possible interaction between cannabis and other medications
  - ratios, ie what is the best THC:CBD ratio for most efficient treatment of the presenting condition
  - conjunctive therapy, ie should different cannabis strains be used together, or different activations of the same strain be used, for the most optimal treatment outcome.
- This leads to the point of education. I am hoping there is some consideration of how to ensure medical practitioners have access to the required information, and that they complete minimum educational requirements, to make informed responses to the queries that may be presented to them, as above?

#### Division 5 – Experimental cannabis licensing scheme

- I strongly support an ongoing Scheme for Research and Experiments with Medicinal Cannabis. I want the questions I posed above (to possibly be directed to a medical professional) to be able to be answered as accurately as possible. This can only be done through research. We want to know what Cannabis strains (or combination of strains), work best for what purpose.
- Here I would like to highlight my strong opinion that whole plant therapy is required when using cannabis as a medicine, in order to allow for the entourage effect to produce optimum medical results.

#### Division 7 – Import and export licensing scheme

- I fully support measures taken to facilitate (and indeed expedite) the import of cannabis products, especially while the Australian industry is in its infancy. I personally know of patients who need to import their cannabis products, which have been proven to be effective for their condition, from the US. This is due to the fact that there is no supply in Australia, legal or illegal, of the exact cannabis product that they require. They need to be able to import now in order to save their child's life.

Thank you very much for taking the time to read my submission. Please do not hesitate to contact me for further clarification of any points I have made.

Regards,  
Hazel Lloyd