

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 father 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 wife 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.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.

The main point I would like to make is that I am aware that Medicinal Cannabis may not work for everybody, just like pharmaceutical drugs. However I am aware of a number of people for whom cannabis has been very effective for conditions very similar to my son. I would like access to cannabis products to be an option for my son, and for others who may benefit.

Thank you very much for taking the time to read my submission.