



Regulator of Medicinal Cannabis 2014

27th February, 2015

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

Re: The Moderator of Medicinal Cannabis Bill 2014

Dear Committee Delegates,

I am the mother of a ten year old child that was diagnosed with Tuberous Sclerosis at the age of five months. As a result of the genetic condition she has been severely epileptic since birth. Prior to starting medication she was having 15-20 seizures a day.

Over her short life she has trialled over twenty anti-epileptics, had two brain surgeries and trialled various diets / supplements. Other than a six month period when she was 18 months old, when we briefly managed to find the perfect balance of medication and brain development, she has never been seizure free. As a result of her epilepsy, she has an intellectual disability diagnosis and currently attends a special needs school. She has also never slept more than a four hour period. She has needed constant care and supervision all her life. As you can imagine, this has placed a huge strain on our family and massive limitations on our lives.

August of 2014 saw us hit a particular low point when Ava's seizures became worse despite being on maximum doses of four anti-epileptics, one of which we were trialling off-label and was costing us almost \$4000 a month. Each of the drugs have horrible, potential side effects. At this time, Ava was having 6-8 seizures a day, some of which were lasting up to ten minutes and sending her back to sleep for hours.

I was able to obtain a few syringes of 18% CBD Hemp Oil and began her at a tiny dose (approx. 1/6ml twice a day). Within a week Ava's seizures completely stopped. Now, six months later, we have completely weaned Ava off of all her medications and she is currently on approx. 1/3ml twice a day. She has the occasional, very small seizure that probably only my husband or myself would notice. A month ago she started sleeping 9-10 hours a night, unbroken.

As you can imagine, this has been absolutely life changing for all of us. We have been able to explore normal lives and realise the potential in our child.

Going forward we would like to see a day where we can travel freely with the oil in our luggage and not worry about the supply we have in our freezer. I believe it needs to be regulated in some way so as to ensure consistency and continuity of product, and also to help bring the price down for struggling families that are already dealing with so much.

I don't have a specific dollar amount that Ava's prior medication regime was costing the government but I would imagine (especially if you take into account surgeries, doctors and therapies) that it was in the hundreds of thousands per year. I am currently paying \$400 a month for the dose of hemp oil that Ava is on, and I would appreciate some assistance with the cost.

I look forward to the opportunity to present my case in person at your inquiry and to bring some supporting evidence from other families that have trialled Hemp Oil for other conditions.

Kind, regards,

Jøelle Neville