

Aaron Johnson & Kelli Russell

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Submission for:

**Medicinal Cannabis**

Victorian Law Reform Commission  
GPO BOX 4637  
Melbourne, VIC 3001

Dear Sir/Madame,

Thank you for giving me the opportunity to contribute to this important inquiry. I have a 2 year old Daughter named Harper who has been diagnosed with Dravet Syndrome with *de novo SCN1A* mutation.

Dravet syndrome, also known as Severe Myoclonic Epilepsy of Infancy (SMEI), is a rare and catastrophic form of intractable epilepsy that begins in infancy. Initial seizures are most often prolonged events and in the second year of life other seizure types begin to emerge. Development remains on track initially, with plateaus and a progressive decline typically beginning in the second year of life. Individuals with Dravet syndrome face a higher incidence of SUDEP (sudden unexplained death in epilepsy) and have associated conditions, which also need to be properly treated and managed.

In her short life, and thus far Harper has endured 35 Tonic Clonic and/or complex Partial seizures, all status epilepticus (30 minutes duration or longer), which in itself are medical emergencies & the most dangerous seizures as they can harm your brain due to lack of oxygen. She has been on life support 4 times, she has endured countless drugs and procedures including intraosseous cannula (IO)(drilling into her shin bone), blood tests, spinal taps, numerous electroencephalogram (EEG), countless Ambulance trips, ICU and hospital stays.

The post seizure period is tough as it often takes Harper a week until she will walk, talk & play again and it is weeks until she will sleep properly. She becomes traumatised after each seizure & will often wake up to 6 or more times a night calling out for her mum.

I have personally dedicated a large portion of my free time over the last 12 months to investigating any possible alternative drugs or therapies for my daughter. My wife spoke about a young girl on an internet group who was on medical cannabis for her seizures. My first reaction was disbelief and confusion. Up until that day cannabis or marijuana was a taboo subject in my families household. I had grown up in a fairly conservative family environment with a focus on sports and the outdoors. We had never touched or used any drug recreationally ever.

The research I have done over the past 12 months relating to cannabis has totally transformed my pre-conceived ideas about this plant. Some of the studies I have read have been nothing short of astonishing. The more I read, the more studies and stories I find of Paediatric Intractable Epilepsy cases either completely seizure free or high percentage reduction in seizure frequency and duration from administration of medicinal cannabis oil.

I have learned of a study that has taken place in NSW by Dr Andrew Katelaris.

Dr Katelaris is one of a very few clinically trained medical professionals in Australia with experience in growing, extracting and administering cannabis medicines. He prepared standardised extracts of a CBD dominant cannabis in medium chain triglyceride oil at a concentration of 5mg/ml and received volunteers requesting their child be included in this pilot study. Twenty children were administered this treatment, half the group being diagnosed with Dravet syndrome and the remainder having congenital, post infectious and post hypoxic aetiologies for their seizures.

Approximately eighty percent of the recipients received benefit and all wished to continue with the medicine. No significant side effects were reported. In about half of the recipients, the benefit was nothing less than transformational. Not only was seizure activity reduced to a minimum or abolished, but the child's capacity for learning and skill acquisition, as well as social interaction was increased, in some instances dramatically.

I have also researched a particular strain of Cannabis Plant that they use in America for Pediatric Epilepsy called Charlotte's Web. This is a strain of medical cannabis processed into a cannabis oil that is high in Cannabidiol (CBD). It does not induce the psychoactive "high" typically associated with recreational marijuana strains that are high in tetrahydrocannabinol (THC). This product is now available to be purchased online through CW Botanicals from the U.S. but importing such products would be committing an offense under numerous state and federal laws.

A big concern of mine is that large pharmaceutical companies with vested interests are influencing doctors and politicians alike. Education and studies are needed into medicinal cannabis and our very own Endo-cannabinoid system, this should not however get in the way of urgent action and law reform to protect those who wish to grow, produce and administer their own medicine in the safety of their own homes. I believe we need to act fast, I cannot wait years for Australian based trials and studies to conclude with findings that are readily available from other countries. Israel, Spain, USA and many other countries have been using medicinal cannabis as a first line of defense drug and not as a last resort.

I believe that we need to give Australians numerous avenues to access cannabis based medicine legally. From pharmaceutical supply, right through to home growing all need to be give due consideration. I believe medicinal cannabis can be produced and tested in Australia, and that Australia has the resources to be a world leader and supplier of medicinal cannabis.

Too many parents like myself are in desperate circumstances, law abiding citizens with a unconscionable choice to make, break the law or watch your child suffer or possibly die, wondering why a government with the power to make change has failed them.

Sincerely yours,

Aaron Johnson & Kelli Russell