

**Submission for** [REDACTED]

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**Inquiry into the Public Health: (Medicinal Cannabis) Bill  
2016**

This document has been prepared on behalf of [REDACTED]  
[REDACTED]  
[REDACTED]

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## Background

██████████ is an 19 year old male who lives with his parents and younger sister, ██████████ in the family home. ██████████ graduated from ██████████ School in December 2015 and spent his primary years at ██████████ School.

██████████ father, ██████████ is a secondary school teacher. His daughter P ██████████ also goes to the same school. ██████████ mother works her time around ██████████ to take him to various medical appointments and runs yoga classes for people with a disability and private classes to support the family financially.

According to ██████████ ██████████ was hospitalised in the Intensive Care Unit from 10 and half weeks old at Royal Children's Hospital, Brisbane. ██████████ had his first seizure around two months near the time he had his first immunisation. He was in hospital care initially for a month and has been on medication since an infant. ██████████ was diagnosed with **Lennox Gastaut Syndrome (LGS)** when he about eight years old. LGS is a type of epilepsy with multiple different types of seizures.

██████████ has pictures of ██████████ going to the beach, swimming, bike riding, horse riding and participating in family activities, like any other child, before the condition set in.

██████████ enjoyed the outdoors up until the age of 14. He showed good social skills and had always been a happy, patient, loving and affectionate young child even though he was diagnosed with the LGS and an Autistic Spectrum Disorder diagnosed around the age of 6.

LGS is difficult to treat because it is resistant to anti-seizure medications. Like many families managing this condition, ██████████ parents have also found, that new medications will decrease seizure activities, for up to two weeks, and then loose its effect soon after. His mother discussed ██████████ enjoying the company of friends and family when they came for barbeques. He also "loved" going camping and participating in fishing trips when the family joined with friends who had kids of similar age in the past. Photos of ██████████ doing these activities have been put together by ██████████

LGS is a permanent condition. With age, the epilepsy may become less of an issue but impaired intellectual functioning and behavioural problems frequently persist. Complete recovery from seizures and normal development is very unusual for those diagnosed with this condition and from years of medications, constant seizure activity (██████████ has experienced up to 150 a day), injuries and head knocks – it is a degenerative and very deteriorating disorder.

## Current Situation

█████ is in receipt of funded supports through the Department of Child Safety, Communities and Disability Services for community access and participation four days per week. █████ parents provide care and support at all other times. As well as his Epilepsy, █████ has also been diagnosed with an intellectual and physical disability, autism, scoliosis, bowel condition and psychiatric issues.

█████ ability to interact in a positive way is dependent on how much sleep he has had the night before due to seizure activities and the medications he is administered. Not sleeping through the night can leave █████ fatigued, tired and less tolerant of things that he would normally be able to manage. Looking after █████ throughout the night has also left his parents tired and exhausted.

The following conditions affect █████ behaviours on a daily basis.

### **Seizure activities**

Seizure activities keep █████ and his family awake during the night leaving him fatigued and agitated the next day.

#### Tonic and Atonic seizures

The most common types of seizures associated with Lennox-Gastaut syndrome are tonic and atonic seizures. █████ has multiple tonic clonics every night from 1 – 12 in total lasting usually 45 sec to 3 mins. After 3 – 5 minutes of fitting, emergency Midazolam has to administered if the seizure does not cease.

#### Epilepticus seizures

█████ had a 10 minute epilepticus (long seizure) in the beginning of February 2016 at home. The family thought that █████ was “going to die” at this time as the seizures were intense and long. █████ reported that ringing an ambulance was not an option any more for them. They have done this many times in the past, to only end up sitting at the hospital for hours, without much intervention, and then sent home. The family would ring an ambulance if needed, but many parents administer Midazolam regularly without the need for medical supervision, or observation.

█████ goes to the Ashgrove Respite Centre in Chiba St for up to three nights every six weeks. His stays have been cancelled many times due to various health complications. According to his family, █████ had two “good weeks” in late December 2015. He was happy, smiling and more engaged. Clinical Services team at Nundah have advocated for █████ to access more respite due to his family expressing feeling exhausted from sleep deprivation supporting █████ during the night.

### The Vegas nerve stimulator (VNS)

█████ received a VNS device in July 2014. This is a **surgical treatment** to reduce the frequency and severity of seizure activities. It involved insertion of a pulse generator, similar to a heart pacemaker, under the skin on █████ chest. It sends intermittent electrical signals to the brain by stimulating the left vagus nerve in the neck. The pulse generator is programmed to stimulate in two ways. It is individually programmed to automatically stimulate in the background, typically ON for 30 seconds and OFF for 3 minutes. The pulse generator can also be manually activated or swiped, in between programmed stimulation times by █████ parents or carers. A special magnet can be placed over the pulse generator to provide extra stimulation at pre-programmed settings. According to █████ █████, the VNS has been “turned up to its limit”. It has shortened the duration of seizures when activated by the external magnet. Activation can be done by both parents only.

VNS was turned down in late 2015 as it was interfering with █████ breathing and sleep (snoring), as well as causing nausea (vomiting). It now largely seems ineffective.

It was reported that █████ who is only 10 years old, often gets up in the middle of the night to swipe her brother’s VNS when she hears him crying out.

### **Medications**

Anti-seizure medications (**AEDs**) can make █████ drowsy and tired. He will appear as if he is “far away” and not hear when others are talking to him. █████ processing time can be further delayed when he has not slept through the night. █████ produced excessive saliva as a side effect to some of his anti-seizure medications.

According to █████ has tried all medications available. It has not been unusual for █████ to have been taking up to 6 different Anti-Epileptic Medications daily throughout the past years such is the resistance of his seizures. They only decrease seizures for two to three weeks and then seizures return after this time.

█████ has trialled **over 20 anti-epileptic drugs** over the past few years including: Phenotoin, Phenobarbitone, Lamictal, Trileptal, Keppra, Clonazepan, Clobazam, Fycompa, Epilim, Stiripentol, Topomax, Diamox, Rivotrol, Zonisamide, Ospolot, Nitrazepam, Rectal Diazepam & Midazolam. There has also been the prescripition of mood drugs/anti psychotics such as: Seroquel, Abilify and Risperidone. The behavioural drugs have caused their own problems including weight gain and fluid retention, depression, irritability and obsessional behaviours.

There are also the regular pain relief medications for constant seizing, spinal and muscle pain from scoliosis, pain from injuries and daily bowel medication, Movicol. When █████ has been sick or unwell, he has also been hospitalised many times as any illness exasperates his condition.

█████ presented with psychosis and was hospitalised for a month in May 2014 at Royal Children's Hospital, Brisbane due to the side effects of all the AEDs he was on. This was another very stressful time for all involved. Since he has had behavioural problems due to the vast amounts of medications prescribed and tested and constant seizure activity.



The scoliosis affects [REDACTED] ability to move his body. He cannot walk unassisted. [REDACTED] uses a wheelchair. At the time of writing, [REDACTED] had fresh injuries to his legs, ankle and arms from falls associated with atonic seizures. He has had many falls over the years due to seizures and medication side effects (unsteadiness on feet, dizziness, malaise.) He has had multiple fractures in right foot, right leg, and right arm. He has had many head injuries including lacerations to the skull, forehead, eye and lips and many teeth injuries. He had a fall in March 2015 where he knocked out a tooth and required hospitalisation and surgery. It was a stressful time for the family. His degree of personal support has increased markedly.

[REDACTED] also wore an **Orthotic Soft Helmet daily** from the age of 6 to as recent as last year 2016 (over 10 years) to help prevent acute injuries to his head from drop seizures, head drops and falls. This was sometimes uncomfortable for him and caused overheating in Summer but had to be worn for his safety.

[REDACTED] wears Ankle Foot Orthotic (AFO) boots

The boots are a special brace that is designed to help control the motion of the ankle joint and also offer support to the foot. It is custom made for [REDACTED]. The brace is used to control painful motion. [REDACTED] requires assistance to walk in these boots.

## **Personal care**

Requires full supervision

[REDACTED] requires full supervision at all times 24/7 especially during showering and toileting. He can weight bear when assisted in his personal care by holding to rails in the bathroom. Using a shower chair, staff support him to wash his hair and body. He can wash his hands but requires staff to operate the taps.

Incontinence

Seizure activities can lessen [REDACTED] ability to control bladder activities. It can take up to two hours to settle and change his sheets when he is incontinent during the night. This process can happen two or three times through the night for [REDACTED] and his parents. According to his mother, bed wetting is embarrassing for [REDACTED] and affects his level of confidence. [REDACTED] wears incontinence aides day and night.

## **Impact and in Conclusion**

As [REDACTED] parents and full time carers, we don't think there is a risk for prescribing Medicinal Cannabis to our son as we have exhausted all avenues of medications and surgery. Comparatively, we think it is relatively safe as opposed to years of ill side effects from all the Anti-Epileptic Drugs. There has been much evidence world wide to suggest the positive effects/results medicinal cannabis oil has on patients like [REDACTED] with uncontrolled seizure disorders including Lennox Gastaut Syndrome/Dravets Syndrome. Although we don't necessarily think it might cure [REDACTED] it may be the **ONE** medication he needs for his quality of life to improve and quality of life to continue for him and our family. There should be no police involvement, legal ramifications or public persecution in our decision for wanting our son to live a happy and normal life like everyone deserves regardless of age, ability, race, sexual identity or beliefs.





## Attachments

Attachment One: Medical report

[REDACTED]