# **Submission for**

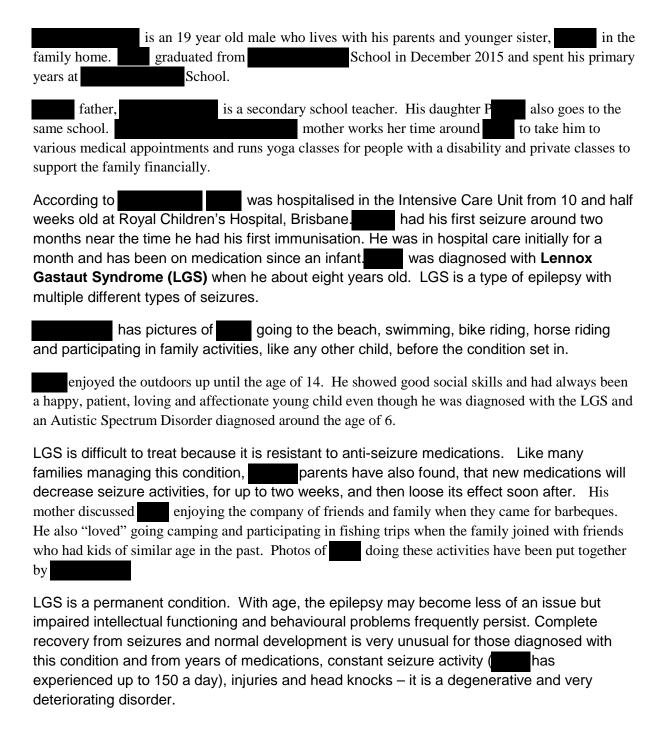
Inquiry into the Public Health: (Medicinal Cannabis) Bill 2016

This document has been prepared on behalf of

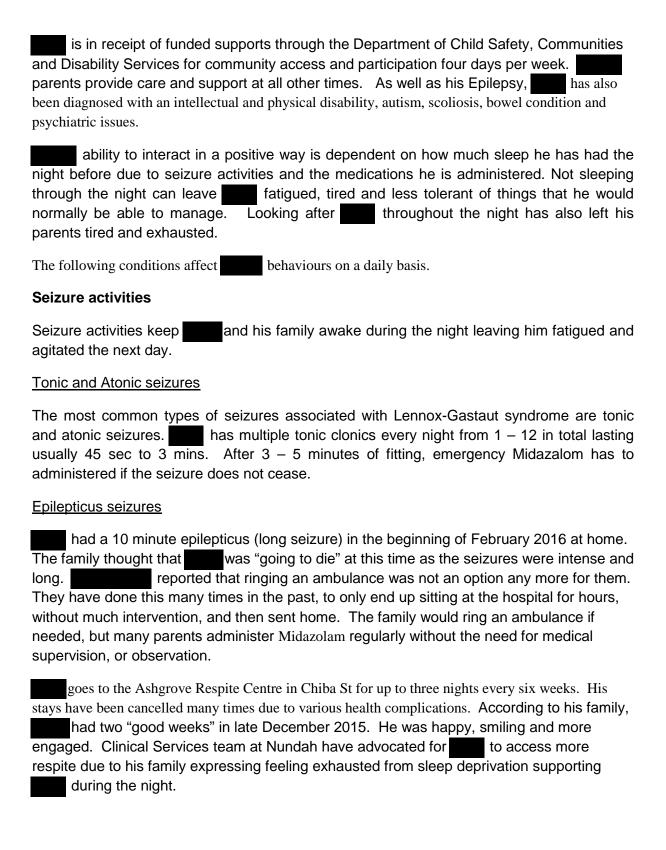
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## **Background**



#### **Current Situation**



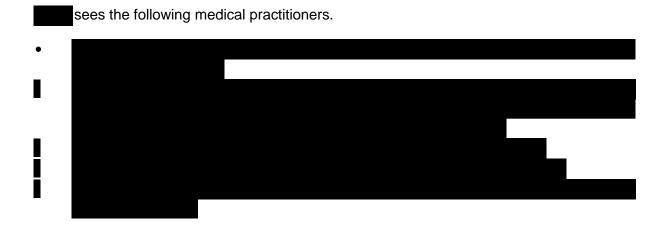
### The Vegas nerve stimulator (VNS)

The vegas herve summator (VNS)
received a VNS device in July 2014. This is a <b>surgical treatment</b> 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 the skin on 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 <b>over 20 anti-epileptic drugs</b> over the past few years including: Phenotoin, Phenobarbitone, Lamictal, Trileptal, Keppra, Clonazepan, Clobazam, Fycompa, Epilim, Stiripentol, Topomax, Diamox, Rivitrol, Zonisamide, Ospolot, Nitrazepam, Rectal Diazepam & Midazalom. There has also been the prescripiton of mood drugs/anti psychotics such as: Seroquel, Abilify and Rispiridone. 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.



Date	Medication brand name	Medication generic name	Purpose	Strength
17/6/16	Frisium	Clobazam	Anti-epileptic	10mg
17/6/16	Epilim	Sodium Valproate	Anti-epileptic	200 and 500 mg tablets
17/6/16	Phenobarbitone Aspen	Phenobarbitone	Anti-epileptic	30mg tablets
176/16	Abilify	Aripiprazole	Anti- psychotic	5mg tablets

Medications change constantly and is not unusual to change every week or two, this also causes paperwork to be updated constantly (ie. respite medication forms) and pharmacy changes and multiple visits.

#### **Mobility**

Daily Medications for as of June 2016

#### **Scoliosis**

has developed scoliosis as defects of the Lennox-Gastaut Syndrome. Scoliosis concerns an abnormal lateral and rotational curvature of the spine. Scoliosis is degenerative over time.

The scoliosis affects ability to move his body. He cannot walk unassisted. uses a wheelchair. At the time of writing, 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.
also wore an <b>Orthotic Soft Helmet daily</b> 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.
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 the brace is used to control painful motion.
Personal care
Requires full supervision
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.
<u>Incontinence</u>
Seizure activities can lessen 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 and his parents. According to his mother, bed wetting is embarrassing for and affects his level of confidence. wears incontinence aides day and night.
Impact and in Conclusion
As 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 with uncontrolled seizure disorders including Lennox Gastaut Syndrome/Dravets Syndrome. Although we don't necessarily think it might cure it may be the <b>ONE</b> 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.

# Recommendations

LGS is difficult to treat because it is resistant to anti-seizure medications.
parents have also found that new medications will decrease seizure activities for up to only two weeks and then loose effect soon after.
seizures can be fatal and cause extreme distress for his family.
has been prescribed several medications for his seizures from a young age which do not result in a long term solution or improve his quality of life. The result of these medications also leads to experiencing psychotic episodes, nightmares and aggressive behaviours.
It would be appropriate for to trial medical cannabis as all other medical interventions have been trialled and exhausted.
Contact details

# **Attachments**

Attachment One: Medical report