



Re: Public Health (Medicinal Cannabis) Bill 2016

Summary

For people with drug resistant focal or generalised epilepsy, who are not candidates for surgery, and have had a VNS implant and are still living with uncontrolled epilepsy there is currently no other therapy available. If medicinal cannabis may help to decrease the burden of the condition by improving the rate or/and severity of seizures for these individuals it would be criminally remiss for any government to prevent this possibility. For this reason I urge the committee to support the submission immediately.

My daughter, [REDACTED], has had uncontrolled and debilitating seizures since birth, is now at nineteen, unable to care for herself in any way and relies on her immediate family and funding from disability services to remain safe and access her community.

An improvement in [REDACTED] seizure status would lead to a number of improvements and benefits to her, our immediate family and the cost to Public Health. These are briefly outlined below.

Public Health Benefits

The benefits of the proposed Cannabis trials and medicinal medication, if successful, would decrease the need and cost of the following for [REDACTED] and others in similar circumstances:

- Less Failed Drug Trials: Twelve to date (Evidence available in hospital and doctor records).
  - Pharmaceutical Supply PBS: Currently on three anticonvulsants daily and a PRN medication that is used fortnightly. (Evidence available via Pharmaceutical Benefits Scheme).
  - Intellectual Harm: is well documented in professional journals, for people on poly anti epileptic medication. This may improve with less medication requiring less support for [REDACTED]
  - Pharmaceutical Error: by the family and professionals could be diminished with less trials and poly therapy.
  - Hospital Admissions for Status Seizures: At Wollongong Hospital, Sydney Children's Hospital, Mona Vale Hospital, Pindara Private Hospital, Ballina Hospital, Lismore Hospital, Mater Children's Brisbane, Royal Brisbane Women's Hospital and Gold Coast University Hospital. She has had fifteen admissions in the last three years, could be decreased. (Evidence available via hospital records).
  - Hospital Admissions Epilepsy investigation/needs: EEG's - week long and day long, Ketogenic Diet, Urologist- kidney stones (medication related broken bones, stitches to head), brain surgery investigations and concussions all resulting from seizures. Implanting of A Vagal Nerve Stimulator in 2012.
  - Health Professionals: Ongoing access to Neurologists and Epilogists, dieticians, physiotherapists and GPs is needed.
- Less access to the Medical Aids Subsidy Scheme and other providers may be lessened.

- Health Services: Blood tests, liver function tests and renal scans are ongoing through her GP and dietician.
- Disability Funding: [REDACTED] is currently accessing programs based on a one to one ratio due to her uncontrolled epilepsy, if it were controlled this could change to a three to one ratio.
- NDIS Funding: At this point in time [REDACTED] will be seeking funding to be supported twenty four hours a day due to her epilepsy.

### Personal and Family Benefits

The benefits of the proposed Cannabis trials and medicinal medication, if successful, would:

- Improve [REDACTED] quality of life in all areas with a reduction of her 360 plus clonic /tonic seizures and numerous daily complex partial and absent seizures.
- Improve her functionality and activities of daily living.
- Improve interaction with her family, peers and community.
- Improve communication skills.
- Provide more access to the community, becoming an active member within the community.
- Result in a decrease in days where she is unable to leave the home due to seizures and recovery time needed and a carer/parent to look after her.  
Provide a decrease in body injury, muscle breakdown and fatigue.
- Overall improved health outcomes by a decrease in poly therapy medications and their side effects.
- Improved sleep for the whole family providing better family health outcomes for all.
- Provide a decrease in diminished working hours and absenteeism for her father.
- Provide a decrease in diminished working hours and absenteeism for her mother and related professional stress.
- Provide opportunity for her mother to access the workplace for more than ten hours a week.
- Result in a decrease in hospital admissions thus improving parental absenteeism or the cost to the taxpayer to provide a carer in hospital.
- Decrease stress with siblings, family members and the marriage.

[REDACTED] currently lives full time at home and is cared for by her father [REDACTED] and mother [REDACTED] [REDACTED]. With a decrease in her seizures we hope to be able to continue to care for her at home. As we are aging the stress and injury we receive from her seizures is affecting our health and therefore our ability for long term care of our daughter.

[REDACTED]