Regulator of Medicinal Cannabis Bill 2014 Submission 109

I want to introduce you to my children.

Tara is now almost 10. In December 2012 after her 8th resuscitation for the year we were told her death would be soon 12-24 months if we were lucky. By this stage she used a wheelchair was not toilet trained, could barely speak and was having around 200 seizures most days. We were planning her funeral. We had even picked songs. Tara's dx's include Dravet syndrome(catastrophic epilepsy) autism, severe language disorder, cp, dyspragia, dyspraxia, anxiety, progressive mental retardation (iq slowly lowering - in December 2012 too low to score), heart murmur, ataxia, drug induced anorexia.

Sean is now about to turn 13. He is a happy year 8 boy thriving in school. Two years ago his anxiety was so high that he could only go to school 2-3 days a week, he was having so many absence seizures that we couldn't count them, over 500 a day at a guess. Whilst these weren't as serious as Tara's they were life altering. He no longer could write or draw due to the severe side effects of meds and had a number of other dx including autism, OCD and drug induced anorexia.

Pharmacy drugs were doing more damage than good, we had hit the end of the road with tara - there were no more options. Well so we were told. Then we found Mullaways medical Cannabis Pty Ltd. Tara was to become the first child in Australia to use medical cannabis to treat epilepsy (well publicly anyway) Tara is a new child, she is now about to celebrate 2 YEARS SEIZURE FREE (3 April 2015) we have weaned all pharmacy drugs, sent back her oxygen and her wheelchair and walking frame are gathering dust in the shed. Tara has now gained enough weight to be considered in the 'average' Catergory. Tara is now toilet trained day and night and her iq is now 59 (maybe even more as that was a year ago) every three hours she takes a dose of medical cannabis. And yes it is administered in school and by her respite agency. Never has this been a issue.

Sean is now 22 months seizure free he will be 2 years seizure free at end of May. He is also pharmacy free. He is your average year eight boy. Sure he still has meltdowns - he is a year 8 boy after all. But now instead of 5-6 hours it is 5-6 minutes. Sean knows when he needs meds and has prevented a lot of seizures by medicating before it happens. Whilst seans changes are not as dramatic as taras they are obvious to us.

What however isn't fair is

- 1. We can not go to hospital
- 2. We can not access very special kids house
- 3. We have been refused as foster carers solely on basis of medical cannabis
- 4. I could potentially loose my children for saving their lives
- 5. Police could charge us for saving their lives
- 6. I could loose my working with children's check if charged.
- 7. My children can legally access this treatment overseas
- 8. You would not take insulin from a diabetic so why is it ok to take the life saving medicine from my child
- 9. Our dr was threatened due to his support of us using medical cannabis -we have signed SAS forms but tga threatened to deregister him if he didn't withdraw support.

Why is my child's life not worth as much as yours?

If it was your child would you not do everything in your power to save them?

Our files can be viewed at

http://www.mullawaysmedicalcannabis.com.au/history/tara.html

Regulator of Medicinal Cannabis Bill 2014 Submission 109

I give permission for all these files to go on public record, to be published whether in print, digital or other form.

We do have a class action ready to be launched to UN courts if this bill is not passed. Names have been gathered and all is ready to go, we simply need to resolve that it can not be resolved locally to move forward. Our solicitor believes we have a very strong case that the denial of medical cannabis is disability discrimination - we will move forward with this lawsuit if it can not be resolved.

Please I beg of you don't forget the 600 plus children already accessing medical cannabis in Australia but more importantly don't leave behind the thousands of adults and children alike that are still waiting. I personally have been contacted by over 10,000 people in need. You can make a difference to them.

Cheri O'Connell