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Our submission for the Medical Cannabis Bill 2014

I write this submission from a unique and personal view of medical cannabis. Firstly up until 12 months ago cannabis or marijuana was taboo in our household as we have never touched or used any type of drug recreationally ever. We are a well-respected family in our community as I have worked tirelessly for families and their children with special needs for many years. I have received a citizen of the year award, 2011 NSW Carers award and many other awards of recognition along the way.

I am the father and fulltime Carer for our beautiful daughter Deisha Magic Stevens. Deisha has a rare genetic syndrome called Rubinstein Taybi Syndrome and was unlucky enough to also have a rare and nasty form of epilepsy called Continues Wave in Slow wave Sleep Syndrome. We have had to call the paramedics many times and Deisha has been hospitalized frequently including ICU stays all due to her epilepsy. The worst is when you find your daughter in bed not breathing due to a seizure. We also have two other children, Summer who is five and Levi who is 3 and they are both healthy.

Over the last 5 years we have had to watch our daughter cognitively regress due to the constant continuous damage to her brain from her uncontrollable seizures and living with the constant fear of Deisha passing away one night from her seizures. We have even taken Deisha to see a world leading neurologist Prof Ingrid Scheffer, who specializes in pediatric epilepsy. Deisha spent a week at the Austin Hospital in Melbourne with Ingrid in October 2013. In March 2014 Deisha was on 7 Anticonvulsants and still having constant seizure activity, with reservations her doctor Prof Annie Bye decided that Deisha needed to also start on long-term daily doses of Prednisone. (A recommendation of Prof Ingrid Scheffer) A steroid that has very nasty side effects including Death, Stroke, Cataracts, Infection, Weight Gain etc etc.. The decision for us to give this to our child knowing the side effects was daunting. Deisha didn't respond positively to the Prednisone and she had to stop taking it and conventional medicine had no more answers for Deisha. We basically had to bring her home and continue to watch her slip away or die from a seizure.

As parents we could not sit back and do nothing to help improve our daughter's quality of life and survival. I started to research on 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) content. It does not induce the psychoactive "high" typically associated with recreational marijuana strains that are high in tetrahydrocannabinol (THC).

I consulted with Deisha's pediatrician and as he said 'What do you have to lose, we have no more answers for you'. I also advised her Neurologist of what we were doing. We were lucky to have a Doctor Andrew Katelaris monitor and supply us with a high CBD cannabis oil. Within 3 days of being on the cannabis oil we started to see positive changes within Deisha. Deisha has now been on the cannabis oil for eleven months and the results have been amazing. She now has no physical seizure activity at all, she is now sleeping all night, her speech has improved dramatically, she can now read and write, she is becoming more independent and she now has the opportunity to enjoy life. Deisha's Pediatrician has called this a miraculous improvement, her neurologist said she is ecstatic with Deisha's improvement and said "David at the end of the day you did this for Deisha, we didn't. " This came on top of after trips to Sydney every 8 weeks to see her neurologist for the past 4 years, we no longer have to go back. I would also like to add that Deisha is also no longer on all those toxic anticonvulsants. Also take into account we no longer need weekly paramedic trips to the hospital, no ICU visits, no stays in the pediatric ward, no trips to Sydney or Brisbane, no weekly visits to the pharmacy for drugs. This has been a huge relief to us as parents and one thing less we have to focus on as I have health issues as well. I was diagnosed with esophageal cancer on March 28 last year.

I would also like to add that I now have used medicinal cannabis myself for going through chemotherapy and my cancer. The results through chemo were amazing, I was originally given anti-nausea medicine for the chemo which turns out to be an antipsychotics drug that just happens to suppress nausea. It did but you also had to deal with

nightmares etc. Medicinal Cannabis gave me instant relief of the nausea and with no side effects. I have also been taking a form of medicinal cannabis oil to help with my cancer and it has managed to contain it rather than spread to other organs.

There has been a lot in the media lately in regards to Medicinal cannabis and many states are at different stages into looking at medicinal cannabis and this is where I have some concerns. Firstly most states have overlooked the benefits of medicinal cannabis for children with refractory epilepsy and this needs to be addressed. As much as NSW has announced trials for children with refractory epilepsy, other states have ignored this or are sitting on their hands and doing nothing while children and their families go through hell and children continue to regress and die. Trials have been done but where the money would be better spent is into medicinal cannabis and why it works and for what other benefits it can be used for. People need to be educated on the medical benefits of medicinal cannabis especially those in the medical field who either continue to deny or ignore the benefits of medicinal cannabis. One concern that has been overlooked and could come with dier consequences is currently there is a lot of media with medicinal cannabis is that people and families are turning to the black market for medicinal cannabis and as much as there are some good people out there making medicinal cannabis there are also some people making oils that aren't what they are supposed to be and desperate families are administering those oils and they don't know what is in it . On a personal level I would like to see this included in all states discussions on medicinal cannabis. We have had such a positive response from Deisha being on CBD cannabis oil that we need to have a guaranteed legal supply especially we don't know on what the future holds for myself. On a broader scale there are other families that are in our situation and don't have anywhere to turn to and the have to watch their child regress or die from refractory epilepsy.

My biggest concern that going forward that this bill and its outcomes will be influenced by pharmaceutical companies who have a vested interest in this and Doctors and politicians who don't have an open mind in regards to medicinal cannabis .This is where education is needed . Don't just look at a single synthetic drug derived from a cannabis plant, you need to look at the whole plant and our cannabinoid system. Look at Israel and Spain and many other countries that have been using medicinal cannabis a first line of defense drug and not as a last resort .

Last year I decided to go public as I believe families need to know that there may be an answer for them out there when they have tried everything else. The Coffs Coast Advocate did a fantastic front page story on Deisha. I have been interviewed on Prime 7 News as well as ABC Radio and the Premier Mike Baird used our family last year for the exclusive in the Sunday Telegraph to announce the trials for children in NSW. All with 100% positive support for us as a family and for Deisha's improved health. On Monday the 29th September I received a phone call from a Community Services case worker to say that they had received a complaint in regards to myself giving Deisha cannabis oil and her welfare. I was absolutely devastated and offended by this claim as we have always done absolutely everything possible to constantly improve Deisha's quality of life. After having them visit us and having our local NSW state member present supporting us. Community Services came back that Deisha was in no danger and supported our use of medicinal cannabis, the case was closed

The actual thought of Deisha or any child not having access to CBD cannabis oil is incomprehensible. That would be putting Deisha at risk. As a parent how could you sit back and stop giving your child something that has improved there life beyond whatever you imagined? I have included a link to a brief video I have put together showing Deisha before and after cannabis oil. Please take the 7 minutes to watch the video and you will understand the pressures we were under when Deisha had seizures and no family should have to go through that when there is an answer. This issue needs to be addressed as I fear with all the media coverage more and more people making cannabis oil in their backyards and families don't know the quality of the product.

Sincerely

David Stevens

Please take 10 minutes out of your life and watch the two videos below and you can help save many lives.

<https://youtu.be/gMGbjGjOoKs>

<https://youtu.be/BqzE1kSjb5U>