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In 1998 our then six year old suffered a devastating encephalopathy. He has been diagnosed with suspected Acute Viral Encephalitis or F.I.R.E.S.

██████████ was a bright happy child, and other than two febrile convulsions at age three was developing normally in every way until this illness. ██████████ was hospitalised for just over a month which saw him admitted to ICU twice, intubated and air lifted to the Royal Children's Hospital in Melbourne where an induced coma failed to quell the seizure activity.

██████████ is diagnosed as having a diffuse brain injury.

██████████ is severely delayed and cognitively functions at a nine month to three year old level.

██████████ is non verbal.

██████████ has severe refractory secondarily generalised seizures.

██████████ has suffered from thousands of tonic clonic seizures, clustering with up to twenty tonic clonic seizures a day at his worst. The longest ██████████ has been seizure free since 1998 is approximately two weeks. ██████████ has constant sub clinical activity. His brain is never quiet. He has seizure foci in every lobe of his brain, he is therefore not a brain surgery candidate.

██████████ has tried and failed every suitable AED (Anti-Epileptic-Drug) for his seizure types. He has suffered a long list of side effects including -

Gum Disease

Severe Insomnia

Weight Gain ██████████ weight ballooned out by 26 kilograms in just six months post diagnosis)

Weight Loss, to the point our Epileptologist was talking anorexia.

Complete Loss of Verbal Skills

Cognitive Delay

Brittle Bones and muscular injuries ██████████ right shoulder is fused, the arthrodesis was performed in 2009 when his shoulder became so unstable that it was permanently dislocated)

Addiction

Drug toxicity ██████████ suffered toxicity most days from the AED's. He would vomit, be ataxic and have blurred vision. This occurred approximately fifteen minutes after dosing with AED's)

Drug Induced Psychosis (Twice once from Keppra when he was approximately eleven years old and then from Vimpat as recent as 2014) We are still dealing with explosive behaviours now even though Vimpat has been weaned. It was as if a switch had been flicked on when we increased per the neurologists advice to target dose of 200mg twice a day. It is proving very difficult to turn that switch off and we fear that this is a permanent long term effect from using this drug.

Respiratory Distress.

██████ was prescribed Midazolam as an emergency measure for prolonged seizures and cluster seizure activity. We were advised to dose generically. ██████ respirations became very laboured and slow. We managed this at home with O2. His neurologist then advised that we administer much more slowly, and over time we have found that ██████ can only be administered Midazolam at a rate of one drop every ten seconds. ██████ cannot be administered more than five milligrams outside the hospital setting. ██████ was administered 20mg of Midazolam as a pre-med for dental work to be done under general anaesthesia. He was in recovery for five hours, unable to maintain his own airways before they decided to reverse.

██████ was implanted with the VNS (Vagal Nerve Stimulator) at age eleven. Initially we saw an improvement in his alertness but no seizure control improvement with the device. The VNS is also a contributor to his severe weight loss when used in conjunction with Keppra he refused to eat.

The decision was made to turn off the VNS by his treating neurologist when a basic lead impedance test saw the diagnostic wand malfunction and the VNS ramped up to the highest mA and caused a chronic severe episode of coughing (A direct side effect of VNS stimulation)

In the eighteen years since ██████ was diagnosed we have only ever defied his treating specialists advice twice.

The first time was when ██████ was around fifteen years old and had already tried and failed every available AED his neurologist wanted to trial him on Sabril. We refused, not wanting to risk his eyesight considering how medication sensitive he is and how refractory his seizures are this was a risk we were not willing to take.

The second time was in 2014 when his neurologist wanted to add a sedative to his daily cocktail of three AED's to try and treat the latest case of drug induced psychosis, and the behaviours and increased insomnia that stemmed from the Vimpat. We refused this option and advised his neurologist that we would be trialling cannabis for ██████.

You may not be able to comprehend what a difficult life ██████ had prior to us giving him cannabis, and eventually weaning almost all of his AED's. It was torturous for him, the side effects debilitating and often dangerous. The AED's were ineffective and he had no hope of ever being free of the side effects.

Our Doctors always told us "If you don't give him these medications, the seizures will kill him" But, slowly and surely the treatment for the seizures was indeed killing him. He had no quality of life.

The decision to use cannabis was not an easy one for us. We researched as best we could with the information that is available, just the same as we had done for every AED that had been prescribed. It was difficult to be outside of his Neurologists care who by his own admission knew nothing about cannabis.

We initially purchased several bottles of oil, when that supply suddenly stopped we started growing ██████ cannabis and extracting the oil ourselves.

By growing his cannabis we know for sure that it is organic, we know the extractions are safe because we make them ourselves. Buying cannabis on the black market is a risky choice, unless you can find a source that is safe and can be provided reliably.

By growing his cannabis we are able to offer him raw cannabis daily to complement his extractions. This has been most beneficial to ██████ general health and well being.

We appreciate the risks in cultivating but this is the safest way to offer him medicines, it is also the only way to have a regular reliable supply.

Prior to cannabis [REDACTED] daily dose of AED's were Lamictal 400mg. Trileptal 1050mg. Vimpat 400mg.

[REDACTED] now takes 75mg Trileptal b.i.d.

[REDACTED] seizures are better controlled, they are less severe. He has not suffered a bout of toxicity since commencing cannabis therapy in July 2014. [REDACTED] is healthier, and spends less time in hospital. [REDACTED] has only required Midazolam once since we started him on cannabis therapy, at all other times we use his cannabis medicines for emergency treatment of prolonged seizures or clusters of seizures. His sleeping patterns are improved and we treat the explosive behaviours successfully with cannabis.

[REDACTED] Specialist is aware of his cannabis treatment and we keep him updated. [REDACTED] GP is aware and encouraged by the success [REDACTED] is having with cannabis and has charted his cannabis therapy on his drug chart/sheet.

As long as we are able to we will continue growing his cannabis and making his oils, despite any changes to the regulations surrounding cannabis in this Country. We will do this just the same as we have always done in advocating for what is right and best for [REDACTED].

I give consent for this document (excluding my address details and phone number) to be used and made public and I am happy to discuss anything further should you need it.

[REDACTED]