Nothing could have prepared me for the moment little miss Isla entered my life. I became her proud momma on Sept 16, 2017 and I instinctively knew something was wrong. We hadn't planned for those 6 weeks spent in the hospital following her birth, so the day we finally went home felt like we had conquered the greatest obstacle we could possibly ever face. We couldn't have been more wrong. That realization hit hard when genetic testing revealed the massively complex and progressive GNAO1 mutation. It is ultra-rare with only about 50 reported cases worldwide. There have been at least 4 known deaths of children under 10 caused by complications with seizures and movement storms.

At 7 months old, Isla suddenly suffered heart and respiratory failure; intractable epilepsy followed in short order. In the midst of her 2nd life-threatening status epilepticus event in less than a month, she was intubated and placed in a medically induced coma. Cardiologists refused her surgery due to seizures and epileptologists told me "there wasn't much hope". We transferred to another pediatric hospital and she arrived in the midst of a 3rd status epilepticus event. She then suffered two cardiac arrests before undergoing open heart surgery a month later. After living in hospitals for 5 months, we were finally homebound!

We enjoyed a blissful seizure free month before the inevitable end of the "honeymoon period". As expected, her body became tolerant of the 4 anti-epileptic drugs she was administered twice daily. After that point, we had near weekly admissions; it was not uncommon for her to suffer upwards of 30 seizures in less than 2 hours with no response to rescue meds. They were usually quite severe and required the use of an AMBU bag to force oxygen into her body in order to prevent brain death and reduce permanent damage. I had to leave my career in interior design to wage a daily battle just to keep my baby alive.

After her 4th status epilepticus event, her epileptologist could only add another drug to her already risky cocktail. As her mother, it feels like a deal with the devil that in order to protect her brain, we put her other organs at risk of failure in the long term. At just 17 months of age, we are already running out of options and seizures are still a near daily battle. Fellow GNAO1 parents have found low THC CBD oil to be incredibly successful in controlling epilepsy and movement storms and many were able to eliminate some of the drugs with the worst side effects. I was apprehensive about discussing this with Isla's neurologists, but found most have seen its benefits firsthand with their own patients whose parents chose to fly under the radar.

These children are being given the very best chance at life, but their family lives in constant fear of the possible repercussions. I am begging you not to ask this of parents in Kansas any longer. I pray that you make the choice to stand with the families of those like Claire, Lola, and Isla who face insurmountable odds and suffering, which could potentially be lessened by the use of low THC CBD oil. No one should have to choose between the law and the wellbeing of their own child.