Oral testimony for House Bill 2282

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Good afternoon respected members of our House Health and Human Services Committee. My name is Kiley Klug and this is my son Owen, who is a happy, laid back 7-year-old. My husband Gavin and I have two sons at home, Dexter, who is 4, and Blake, who is 1.

Owen has been on quite a journey in his brief 7 years of life. He was brought into this world to us after a completely normal pregnancy and childbirth. Owen was developing normally and thriving until six months of age. I remember the phone call from my husband like it was yesterday. I was on my way to chaperone a middle school dance. Gavin was frantic. He was feeding Owen, and I remember him screaming, "Kiley, something's wrong. Owen's eyes are rolling to the back of his head. I think he's having a seizure." Everything changed in that one pivotal moment in our lives.

We spent the next four years in hospitals and clinics while they administered genetic testing and diagnostic procedures to determine what was causing Owen's seizures. Owen began significantly falling behind developmentally as well. The seizures would come and go, and his development would follow suit depending on the seizure frequency at the time. By his second birthday, Owen was having multiple seizures daily. He endured MRIs, EEGs, CT scans, spinal taps, surgeries, extensive genetic testing, and trips around the country to top neurological specialists. A video EEG conducted when Owen was three years old showed he had over 200 seizures in an 18-hour period. At the age of four, Owen was diagnosed with Dravet Syndrome. Since then, we have tried everything including: a combination of 8 different pharmaceutical medications, acupuncture, a ventricular nerve stimulator (VNS), oil therapy, special diets including but not limited to the ketogenic diet, and other various wholistic treatments, for example cranial-sacrum. We have tried everything available to us in the current situation we are in. Gavin and I believe we have religiously, almost to a fault, followed Owen's doctors' recommendations. For example, at one point Owen's neurologist had him on both the ketogenic diet and four pharmaceutical medications. Owen was so incoherent that he couldn't even focus to eat his food. I would spend literally an hour shoving the carefully measured out food down his throat, only to have him vomit it up in the end. Owen regurgitated three meals a day for three months before his doctor hospitalized him and immediately cold-turkey weaned him off of two of the four medications.

Unfortunately, after everything we have tried, Owen continues to seize an estimated 10-40 times a day....and that number only includes the seizures we visibly see. I think it's important to note that Owen's development hugely relies on seizure control. His development is a roller

coaster; one month he will be able to sit independently for 30 minutes at a time, and the next month he cannot sit for more than ten seconds. He used to walk in a walker, hold his own cup, and babble "mama" and "dada." I can't even convey how difficult it has been to watch our son decline and struggle. However, on a positive note, once his seizures are even remotely controlled, he could possibly begin to communicate and become more mobile. Owen's developmental future is an open book. I'm standing here today asking you to write the next chapter, and that chapter involves Owen gaining access to cannabis oil in the hopes that his seizures would be at least decreased if not controlled.

Committee members, I am respectfully by all means in support of whole-plant medical-only legislation. However, I realize that the Kansas government is ready for neither SB9 nor HB2011 at this time. And at this time, I am ok with that. As Owen's mother, I am asking you to consider this compromise bill of HB2282. This bill would at least allow Owen to legally access three or four strains of high CBD oil to try, yet is restrictive enough to ease the hesitant mind at this time.

I cannot stress enough that Owen has nothing else to try in this state. Please allow him access to a natural, safe, non-hallucinogenic medication that could give him a chance to be present in this life.