Patient Testimony/SB9 Proponent

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Good afternoon esteemed members of our Kansas Public Health and Welfare 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. I am by trade an educator but my career has taken a backseat to both Owen's health issues and my youngest son Blake's, who was just diagnosed with Type I diabetes right before his first birthday.

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. This sweet baby boy was my husband and I's saving grace after unexpectedly, tragically losing our healthy, full-term baby girl Halle at birth just a year prior. 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 holistic treatments. 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. Unfortunately, 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 learn a skill, only to lose it a short time later. 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, and you have a chance to write possibly the most important chapter!

Committee members, this is what I know. My husband and I are born and raised Kansans. We are practicing Catholics. We are conservative. We are educated. We have high moral standards. We obey the laws of this great state. But above all of those things, we are desperate parents who will do anything for our child. We have been backed up against a wall. Owen is honestly and literally out of options in the state of Kansas. The one option that could possibly change his life for the better could send us to jail and take our children away from us. I could sit here and provide mounds of research about the millions in revenue medical cannabis legalization would bring to our great state. I could go on and on about the possible benefits and lack of side effects of cannabis oil versus the harmful, FDA-approved pharmaceutical medications he is ingesting. But I won't. If you hear anything from my mouth today, hear this. We can neither wait for research nor worry about the risks or side effects of medical cannabis. Unfortunately, Owen has reached the last-resort phase of treatment. The risk of him dying in his sleep from a seizure haunts my husband and me every day. We know this medicine has worked for other children just like Owen; these children are speaking, swimming, biking, and interacting. Owen deserves this same chance to thrive! We cannot be concerned about medical cannabis opening a door for recreational legalization. Recreational use is a non-issue here. Please, pull back all of the layers to this controversial issue, clear your minds of all the negativity and stigma, and look this little boy straight in the eye. Please do the right thing for him. This is what your political career is all about, helping Kansans live the best lives possible. Owen needs you. Be his hero today. I can promise you this. You will NEVER regret helping this innocent child.

Madam Chairman, I realize that perfecting a bill takes time and compromise. I am by no means expecting a cannabis dispensary on every corner in Kansas. I am just a desperate mother pleading for help for my son. Thank you so much.