Kansas Senate Bill 9- Cannabis Compassionate Care Act

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My name is Tiffanie Krentz. My husband, Kevin and I live in Topeka and have 2 beautiful boys, Jacob Jerome 'JJ' age 10 and Jude, age 7. We are traditionally a conservative family whose lives have been changed by a devastating syndrome.

Our oldest, JJ suffered his first seizure at 6 months of age. It lasted 45 minutes, we spent the afternoon in the ER as he was put through a lot of medical tests but left the ER thinking this was a onetime event caused by a fever. Unfortunately that was not the case. A month later, I took JJ out of the bath and he started seizing, it did not stop. After calling 911 JJ was transported 'Code Red' to the ER again. This time he was sent to Kansas City and admitted to a pediatric Intensive Care Unit. JJ had an ear infection but the fever caused uncontrollable seizures. By 9 months of age, JJ was no longer meeting his developmental milestones. The seizures became not a monthly event but daily. JJ would suffer 3-5 tonic clonic seizures a day, anytime of day with no warning. On top of the 'big' seizures JJ suffered 100's of myoclonic seizures.

Medications were not working for JJ, he had no diagnosis. We saw 5 pediatric neurologist, traveling to St. Louis and the Mayo Clinic seeking direction, help and a diagnosis. We started JJ on the Ketogenic Diet at age 2. He failed it in addition to all the meds he had been given. We were using Diastat (an emergency medication) 2-3 times a week. Countless ambulance rides, ER visits, hospital admissions which almost always started in the PICU, more doctors' appointments and medical tests than any one child should have to endure.

Through my research and begging Doctors to test our son we finally received a Diagnosis, Severe Myoclonic Epilepsy of Infancy, now known as Dravet Syndrome. Dravet Syndrome is considered a catastrophic epilepsy syndrome. It is genetic and affects the SCN1A gene. In addition to severe epilepsy, which is extremely difficult to control and can be fatal through status or SUDEP, JJ is severely cognitively delayed, he has Autism and is considered medically fragile. JJ is no longer able to eat orally and is fed through a GTube.

There are approximately 26 classes of anti-epileptic medications. Of those, JJ has been on 16 of them. Seizures associated with Dravet are very difficult to control and there are only a few medications known to control the seizures the best, often used in combination: Topamax, Depakote, Onfi and l-which is not FDA approved and therefore not an option for us.

JJ is on Topamax, Onfi and takes Clonazepam. JJ also has a VNS and is on the Ketogenic Diet. In 2012, JJ's seizure medication regimen included Depakote as well. Although JJ had been on Depakote for 3 years he suddenly became very ill. We were admitted to the hospital in Topeka, the doctors were unable to find why JJ had become so ill, his Kidneys were not working properly and he was vomiting profusely. We were transferred to Kansas City again. After a week the doctors finally came up with a

diagnosis: Fanconi Syndrome. Fanconi is a VERY rare side effect of Depakote. The result? The effects include a significate bone density loss and we are left with no medication options for JJ to help control his seizures.

JJ's seizures are relatively controlled now however he is 10 with Puberty right around the corner. With Dravet, puberty can be devastating. Often seizure control is lost, cognitive and physical decline often occurs. We have done everything in our power to ensure JJ has been able to have the best quality of life possible, we have taken him to every doctor possible, we have ensured he has received OT, PT and Speech Therapy. JJ has been the center focus of our entire family. There isn't anything we haven't tried. In 2013, his neurologist suggested out of home placement due to the number of behavioral challenges and seizures we were dealing with. I was absolutely opposed, I am his mother. His doctor told me we should look at a short term placement. On June 3, 2014 JJ was admitted to Parsons State Hospital. That short term placement has become permanent for the foreseeable future. I did not see how challenging our life was, in fact until his first home visit I was still under the delusion I could care for him. I was so wrong. Without significant help we can no longer safely care for a child who is unable to express himself, not toilet trained, can push me around physically, has not concept of safety and has is Gtube fed and this is on top of dealing with his seizures.

I am very aware of the benefits that Cannabis can provide. I have met parents who are using CBD with their children and seeing amazing results. The family that has been on the forefront nationally fighting for Medical Cannabis rights has a daughter with Dravet. I know that it may not work for JJ but what I am absolutely afraid of is not having access to it for him. Why should my child be denied something that has shown true benefit? The arguments against medical cannabis can be a mile long but this is MY response as a parent of a child with a horrible syndrome:

1.My son could have died from a side effects of a prescribe medication when he developed Fanconi Syndrome.

2. My son's body is addicted to benzos-weaning him off of clonazepam is not safe for him, the weaning process can cause seizures and I am not willing to risk losing him because his body needs a prescribed medication. Benzo withdrawl can be deadly.

3. Due to the number of benzos JJ has taken over the years stopping his seizures is more and more difficult as his body has developed a tolerance for them.

4. JJ takes more medication to counter act the side effects of the seizure medications than the seizure meds themselves-he has taken 16 different seizure medications in his short life.

5. Medical Cannabis has shown to be safer than many prescription drugs and what could possibly be worse than have a child who's body is a addicted to prescription medications that are in fact known to be deadly.

6. I am not a doctor or scientist. I am a mother who has spent 10 years dedicated to finding the best possible treatment for her son. All we have ever wanted was to provide JJ with the best quality of life possible. We have wanted no more than any other parent. Just a happy, healthy child. We have done everything possible, everything every doctor has told us to try, including placing our child outside the home. There is nothing short of death more devastating than not being able to care for your own child.

I know medical cannabis may not work for JJ but the thought of not being able to try one last thing for him because of the legal status is more than heartbreaking. As JJ reaches puberty I can only pray we won't lose him. Kevin and I are fearful of the future and wonder if we could have tried medical cannabis when he was younger would we still have him at home with us where he belongs? Would we have to watch our 7 year cry because his brother is sick and we cannot properly give him what he needs? We do not know. We do know there would be nothing to lose by trying it, nothing, prescriptions have almost killed and slowly the side effects of the medications he is on are.

I pray upon this committee to send this bill to the Senate for full debate. I don't know what the future holds for us, I know that you literally have the ability to change the lives of many children and families in the great state of Kansas. Thank you for your time and consideration.