Kansas Senate Bill 147 Authorizing hemp treatments for seizure disorders

Proponent Testimony

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I am here today in support SB147 on behalf of my husband, Kevin and for our son JJ. Kevin and I live in Topeka and we have two amazing sons, JJ, age 11 and Jude, at 8.

Like most couples we were over the moon when we brought our first born home. We excited to start our life with our first child. On December 29, 2004 our lives changed forever. JJ suffered his first seizure, lasting 45 minutes, his O2 stats dropped to 39%. When we arrived at the ER we were escorted into the family waiting room and were not permitted to go back with. A Chaplin sat with us and tried to give us comfort, but no one knew what was happening. When we were finally allowed to see our son, there were still 8 people in the room working on him. That afternoon as we sat in the ER with him, wasn't responsive and we thought we would lose him. After all the tests were complete the only thing they could find was JJ had an ear infection. Doctors thought the seizure must have been brought on by a fever and told us they didn't think it would happen again. 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 another ear infection but this time the fever caused uncontrollable seizures. By 9 months of age, JJ was no longer meeting his developmental milestones. The seizures became a daily event. JJ started suffering 3-5 tonic clonic seizures a day, anytime of day or night with no warning. On top of the 'big' seizures JJ suffered 100's of 'smaller' seizures. In fact after being admitted for a 48 hr EEG, JJ was released after only 18 hours because brain activity was showing so much seizure activity.

Medications were not working for JJ, he had no diagnosis. We saw 5 pediatric neurologist, from those at KU Med and Children's Mercy. We even traveled 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 epilepticus 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 medications in 13 of these class 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 one-which is not FDA approved and therefore not an option for us.

Currently, is on Topamax, Onfi and takes Clonazepam. JJ also has a VNS and is on the Ketogenic Diet again. 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? JJ was discharged from hospital after 3 weeks, unable to walk, and barely talking. It took 9 months of continued treatment with IV medications to get his body and kidneys functioning again. However, the long term consequences have resulted in significant bone density loss and we are left with no medical options for JJ to help control his seizures.

Puberty is right around the corner and while we have finally accepted we have the best seizure control possible given the medical options we have we fear the worst. Puberty is often difficult for anyone with Epilepsy however with Dravet, puberty can be devastating. Often seizure control is lost, SUDEP (Sudden Unexplained Death of Epilepsy) becomes an even bigger fear for us. With the loss of seizure control JJ will lose cognitive skills we have fought so hard for him to gain.

We have done everything in our power to ensure JJ has the best quality of life possible, we have taken him multiple doctors; 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 and has no concept of safety. One of my least favorite tasks is putting his Gtube back after he has pulled it out because he is angry/sad/hurting/frustrated or just being plan ornery.

I know Therapeutic Hemp Oil is an option for many to try but we haven't had that opportunity due to the current laws in place in Kansas. I have met parents who are using CBD with their children and seeing amazing results. I am realistic. It may not help JJ but like any other AED it is the same. In fact anytime a new AED is introduced we are told, it will significantly help 1/3, it will help a 1/3 some and the other 1/3 will see no change. So for me it is a no brainer to have that option to try. If it doesn't work I know it won't kill him like some of the medications we give him can.

Nothing can cure our son but SB147 may be JJ's last option for him when his current AED regimen fails. I cannot just stay on the sidelines and wait for another pharmaceutical drug. I know for a fact that my son could have died from the side effects of a prescribe medication

when he developed Fanconi Syndrome. JJ's body is also addicted to benzos and weaning him off of clonazepam is not safe for him and can be deadly. The weaning process can cause seizures and I am not willing to risk losing him because his body needs a prescribed medication. 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. A very real fear for us is JJ will end up in Status Epilepticus (prolonged seizure) that the doctors cannot stop and he will end up in coma or worse. This fear was brought to the forefront just last month when the American Epilepsy Society released guidelines for Status Treatment. After 40 minutes there is no known protocol to stop a seizure. It is imperative every action is taken to stop the seizure before the 30 minute mark.

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. I have gone back and reviewed the number of medications JJ has been prescribed over the years. JJ has ingested over 100,000 pills or oral medications since we began this journey with him at the age of 6 months old. How can we not expect that those drugs have caused long term harm for him? CBD oil with low THC may even give JJ the opportunity to wean off clonazepam.

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. Every medical decision affects the life or death of my child. We have signed a DNR for JJ and have a cemetery plot and funeral plans made. We have been forced to acknowledge we may have to bury our son someday. If that day comes, we want his life celebrated as we know and love him. JJ is a gift to all of us. We need to protect our gifts. It is time for Kansas to be part of protecting him and give him access to CBD oil.