Kansas House Health & Human Services Committee

HB 2152

Oral Testimony Wednesday, March 15, 2015 1:30pm

My name is Tiffanie Krentz. By now some of you have heard our story several time. My husband, Kevin and I live in Topeka and have 2 beautiful boys, Jacob Jerome 'JJ' age 12 and Jude, age 9. We are proud Catholics and a traditionally conservative family whose lives have been changed by a devastating syndrome. JJ is not with us today as he is a resident on the medical cottage at Parsons State hospital. JJ is doing amazing at Parsons due to the quick medical attention and structure he is given. JJ has the best quality of life he ever has and we are eternally grateful for the care he is given. We now have had the opportunity to see what JJ is capable of and who he really is. For us though, we are left at home to grieve. It is actually harder for us day to day not to have him home but we could no longer give him what he needed to thrive and stay healthy. JJ actually is right where he should be and he even seems to know it.

Today I am here to ask you to pass HB 2152 through the committee and to the House floor for debate and ultimately approval. HB 2152 must be given the opportunity to be heard on the House floor. The reason? Families are still at risk of prosecution in the State of Kansas if they are caught giving their loved one CBD oil, even at the dose proposed in this bill. While CDB is federally legal at this dose is it not legal in Kansas to use.

Today I am advocating for families like ours who have a child with a horrible syndrome and are at a loss. Our story begins like most couples whose world is rocked by a catastrophic syndrome. We were thrilled to bring our first born home and 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, 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 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, and Onfi.

Currently, is on Topamax, Onfi, Clonazepam, he 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.

We have done everything in our power to ensure JJ has the best quality of life possible, we have taken him to 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 G-tube back after he has pulled it out because he is angry/sad/hurting/frustrated or just being plan ornery.

So why now? Why are we asking you to send this Bill to the house floor? I have met parents who are using CBD with their children and seeing amazing results. Every day we wake up to an empty room, a room with a hospital bed, oxygen tank, locked cabinets filled with medical supplies, JJ's favorite toys sitting where he left them at his last home visit. We can't help but wonder if CBD would have helped JJ? Would he still be at home? Would his body still be addicted to benzodiazepines? We will never know. However, if one family could find some relief and not be worried about where the state will come after if they give their child federally legal CBD oil then that is one family who can still be whole. CBD oil may not work for all but it is no different than any other AED we have ever tried yet there are no side effects. 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. JJ may never use CBD oil and if he did have the opportunity to legally use it in this state it may not work for him. But to take that opportunity away for desperate families is something we as Kansans are better than. As I conclude my testimony I want to stress to you again, we I know for a fact that our son could have died from a side effects of a prescribe medication when he developed Fanconi Syndrome. JJ's body is addicted to benzos and 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 withdrawal can be deadly. 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. 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. Therapeutic Hemp Oil has no side effects.

I pray this committee will pass this bill on to the full House and do the right thing. Give Kansas families the opportunity to give their child something already federally legal and not worry about the State of Kansas. Families of medically fragile children are tired and exhausted and adding fear of state prosecution to the list of stressors we are under should not be one. Kansas can do better for its children and families. The opportunity for any improvement in any part life for children like our JJ is worth it. I don't know what the future holds for JJ and our family but I know 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.

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