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Proponent of SB147

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I am the mother of Charlie, a cute little 2.5 year old boy who lives in Hays and who would benefit from you bringing the SB147 bill to the floor to be heard—again. I am attaching a picture for you, so that you can see that from the outside, Charlie looks like any other child. He's ornery, loving and handsome.

However, I also see a little boy who has to give up minutes of his life every week due to seizures. You see Charlie has Dravet Syndrome, an intractable epilepsy syndrome that is resistant to current pharmaceuticals. And one day those minutes are going to turn into hours—they have before. Because, that's what Dravet Syndrome does. He has tried and failed multiple pharmaceuticals and the current medications he is on now are starting to become less effective as well and we are at our limit for any increases in his current drugs or for trying anything new. Not only are the medications he's on now starting to fail him but they're causing horrible side effects: *trouble sleeping, muscle spasms, agitation, aggressiveness, restlessness, hyperactivity, irritability, reduced attention, loss of appetite, poor coordination, unsteadiness, mood and behavior changes, addiction...* and these are just the ones we've seen.

We have also tried other methods for controlling his seizures. Other treatments and therapies that have shown positive results in the overall care and management of Dravet syndrome in some patients, include VNS (Vagus Nerve Stimulation) Therapy, Charlie is too young for that—age 9 is the soonest his doctor would agree to it, and even then it only works 50% of the time. The ketogenic diet works for 2/3 of those who try it; we are sadly part of the 1/3 it doesn't help. Families also have reported that the use of CBD (cannabidiol) has been beneficial with both seizure management and cognition. And this is where we are at now.

We have added hemp oil to his diet and can tell that it has helped his cognitive development. It has taken him from 18 words to 40 in just a two week period and that isn't coincidence. However, with everything Dravet I know that the current hemp oil we use will become ineffective and we will need access to a higher level that may also help control his seizures and hopefully even one day let us wean him off his current medications and relieve him of their horrible side effects. I know a big argument against CBD oil is that we don't want to be getting children high. Sorry to tell you but I get my son high every time I have given him his rescue medication to stop his seizures, which was twice in the past week. I would rather have access to a drug that doesn't have as many nor as horrible side effects as his current medications. As a mother I plead with you to take a moment to try and step into my shoes and ask yourself what would you do?

I hope and pray that you took the time to read this. Let it all sink in. Think about my little boy and think about how someday he may not be able to run around like he can right now, how he may lose the 40 words he's able to say now, how he may lose his life completely in the middle of the night without warning. Just because he looks fine on the outside, doesn't mean he isn't fighting a horrible monster on the inside. Think about him this Easter and pray that it is not like last year when we had to leave the Easter egg hunt we were at because he starting seizing in the middle of trying to pick up an egg. Please think about us and the other families in Kansas that are dealing with this same exact syndrome, and all those with other conditions that could be fixed by simply bring this bill to the floor and being voted yes on.

Thank you for your time. If you have any questions I am more than happy to discuss more with you. Have a wonderful weekend.

Sincerely,

Ashley Bergman

