

Federal & State Affairs Committee Testimony

Date of hearing: Monday February 20th
10:30am Room 144

Bill Number: SB155
Enacting the Cannabis Compassionate Care Act

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Agency Represented: N/A

Proponent Oral testimony
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My name is Melissa Ragsdale, mother of four boys and lifetime resident of Kansas. I support SB155 Enacting the Compassionate Care Act for Kansas patients. I ask the committee members for their support in passing this legislation.

My son Gavin is 7 years old and suffers from Myoclonic Astatic Epilepsy or Doose Syndrome Epilepsy. Doose syndrome is categorized as difficult to treat and often drug resistant. Gavin has 6 seizure types, that occur all over the brain, as opposed to one focal area. . When dealing with 6 seizure types, multiple drugs are prescribed. One drug may stop one seizure type, but will not control other types happening. In Gavin's case, each drug would stop one seizure type, while significantly aggravating other types. These medications are highly toxic (to the organs in the body), highly addictive, with adverse side effects that can be deadly.

Some of the side effects that Gavin suffered include tremors, stomach (digestive) problems, headaches, confusion, drooling, fits of rage, hallucinations, uncontrollable crying spells, significant increase in seizures, and most devastating as a parent, loss of personality and cognitive function.

Gavin was so heavily drugged, he was no longer able to recognize letters, colors, or shapes, he was unable to write anything but scribbles. The medications completely destroyed his cognitive function and abilities to learn and retain information. The neurologists kept telling us that what we were seeing was "typical of his type of epilepsy." But I knew in my heart and instincts it was the caustic pharmaceuticals.

In May 2014 Gavin had 20 seizures in an hour. That's a seizure every 3 Minutes. We administered his rescue medicine, but he continued to seize. Gavin was admitted to Children's Mercy Hospital where he was given more AED's (Anti-Epileptic Drugs). But nothing would stop his seizures, in fact seizures became so frequent that hospital nurses told me to stop logging. In just a few days my, then 5 years old, had been given ONFI, Topamax, Depakote, Valium and Lacosamide. Powerful psychoactive and addictive synthetic drugs. The seizures persisted. After several days we were sent home devastated.... With another prescription for Felbamate. (It was never filled).

Once home, Gavin was unable to walk or talk. He just sat on the couch seizing and drooling from medications. My son was being drugged to death and I was certain Gavin was going to die. Not from Doose Syndrome Epilepsy, but from the cocktail of pharmaceutical drugs prescribed by his doctors.

We had been researching cannabis and hemp and found a company that imports industrial hemp CBD. This product had a THC content of .01 THC. Federal guidelines as a dietary supplement is .03 THC or under. We decided to have it rush ordered.

Within hours of his first dose our baby boy started saying Mom and Dad. The second day Gavin started talking and walking. The third day my little boy was dancing and singing "Who let the dogs out."

It was like winning the lottery. We were slowly getting Gavin back. After several weeks on CBD we had our very first seizure free day.

Over the course of several months, using industrial Hemp CBD, we slowly weaned each medication, one at a time. Gavin's cognitive function improved Tenfold.

We enrolled Gavin in kindergarten in August of 2014 . Just that previous May, it was not going to be an option for Gavin to attend school with his peers. Gavin was literally starting over. He had to relearn absolutely everything. Gavin is a special needs student and has a para assigned to accompany him at all times.

Gavin continued seizure free until November 2014. At first it was just a few seizures a day. We were advised to increase the CBD, but it only increased his seizure activity.

We tried rebooting his system. This meant stopping the oil for a few days and restarting. We tried different dosing recommendations and different products but we couldn't regain control. Gavin has never had a seizure free day since.

Gavin currently has between 20 & 100 seizures a day. That doesn't include nocturnal seizures. This directly affects his ability to learn and retain information as his brain is constantly being interrupted.

Gavin wants more than anything to be a normal kid. He wants to play football, baseball, play on the playground at school with all of his friends and because of his severe epilepsy those things are not an option for him.

In February of 2015 his neurologist looked me in the eyes and told me if it was his son he would take him to a state with medical cannabis. That was absolutely devastating. These doctors want to be able to help our kids, to research cannabis, they want to be capable to prescribe cannabis. Yet these doctors cannot. Kansas state and federal laws are prohibiting valuable research and preventing doctors and patients from access.

I began reaching out to experts across the country who were working with cannabis to find out why CBD was no longer working I started researching everything I could about the endocannabinoid system. We thought CBD was our miracle, but we were wrong. We were seriously uneducated about cannabis as medicine, and HOW it works within the body.

One of the first things I found out was that the NIH (National Institute of Health) has a patent for cannabis. Patent number 6630507, Cannabis as a neuroprotectant and antioxidant. At the same time cannabis remains as a schedule 1 drug “claiming” no medicinal value. This not only contradicts this patent from 2004, it also contradicts all the other patents for cannabis dating back to 1940.

The endocannabinoid system (ECS) is an intercellular communication system. We all have both CB-1 and CB-2 receptors. Endocannabinoids and their receptors are found throughout the body, working for one goal, to create homeostasis within the body. THC plays a very important role in opening up these receptors allowing other cannabinoids like CBD to work synergistically. In other words, THC allows these cannabinoids to work more efficiently. We know cannabis has over 100 different cannabinoids as well as flavonoids and terpenes that affect how the plant works medicinally for each individual. Each component should be recognized as equally important. Similar to DNA, every person has a unique endocannabinoid system. The need for certain cannabinoids varies from each individual and the ailment they are seeking to treat. Limiting patients to CBD only, from the wide range of beneficial cannabinoids, prevents the endocannabinoid system from doing its job, creating homeostasis within the body and bringing relief to the patient.

When dealing with seizure types that occur in different areas on the brain, multiple drugs are prescribed. One drug may stop one seizure type, but will not control other types happening in different areas of the brain. The problem is these medications are highly toxic (to the organs in the body), highly addictive, with adverse side effects that can be deadly. Cannabis can be used in the same fashion as pharmaceuticals, but safely, without toxicity and without dangerous side effects, or damaging internal organs.

Gavin has not had a single Grand Mal seizure or hospitalization in the 2 ½ years using Hemp CBD. Unfortunately CBD alone can only stop two of his six seizure types. Gavin must wear a medical helmet to protect him from head injuries, as he continues to be plagued by constant atonic drop attacks and absence seizures. Gavin will require the use of THC, THCa, and other cannabinoids to control his multiple seizure types.

We feel extremely blessed to have been able to remove the toxic pharmaceuticals and see Gavin slowly regain all of his cognitive abilities. He is now in the second grade and performing at a first grade academic level. He is constantly interrupted by seizures throughout his day at school. Often times losing several minutes before and after his seizures, causing him to have to start over

because he will not retain the information when these interruptions occur. We fully believe that access to cannabis can eliminate or significantly reduce his other seizure types, allowing him to I found many caregivers treating their children suffering from Doose Syndrome in States that have access to full spectrum medical cannabis. Some of these families were forced to move to gain legal access, becoming American medical cannabis refugees. Many of these children are up to 98% seizure free and off all toxic pharmaceuticals. The majority treating pediatric epilepsy with multiple seizure types, are using multiple strains and using low, to no CBD, and high THC strains. These children are not “high”, like they were on pharmaceuticals, but THRIVING thanks to access to THC.

Cannabis should be used as an individualized medicine because that is truly how it is meant to work. One strain or cannabinoid ratio may work for one patient with epilepsy and will not for another. Cannabis is utilized to treat patients with epilepsy, alzheimer's, MS, parkinson's, cancer, anxiety disorders, PTSD, the list of conditions cannabis can bring relief goes into the hundreds. Every ailment revolves around the ECS. Every patient's endocannabinoid system must be “fed” differently to bring relief.

I urge Kansas legislators to say NO to CBD only legislation. CBD only laws have failed to bring relief to patients in every State that has enacted this limited legislation. The Federal Farm Bill of 2014, section 7606 allows for the legal cultivation of hemp in the United States. Companies such as The Flowering Hope Foundation (Haleigh’s Hope), Synergistic Research (Palmetto Harmony) and Realm of Caring (Charlotte's Web) and many others, are producing Hemp CBD .03% (or less) THC and are legally shipping to ALL 50 States. These companies are even able to ship to countries outside of the United States, as they are growing in full compliance with the Federal Farm bills regulations.

Hemp CBD and naturally recurring cannabinoids therein, are NOT included in the controlled substance act and have always been shipped into the United States. Patients will NOT benefit from “medical hemp” legislation in Kansas. CBD only legislation shows a complete lack of education and research regarding the science behind the endocannabinoid system and should not be considered by the Kansas legislature. Furthermore, the use and treatment of cannabis should not be dictated by the government, but should be between patients and their doctors.

Kansas legislators have the opportunity to provide full spectrum relief and protection to patients. I ask you to support this bill and give Kansas patients the opportunity to have legal access to the single most important medicine of the 21st century, cannabis.

Thank you for your attention to this important issue,

Melissa Ragsdale

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