

My name is Melissa Ragsdale. I am asking the Kansas legislature to take immediate action to pass a comprehensive medical cannabis program this session. Kansans overwhelmingly support safe access to medical cannabis. While I support medical cannabis in Kansas, I strongly disagree with HB 2184 and urge you to adopt the language from SB 92.

Our family spent many years fighting for access to medical cannabis in Kansas. Our cries for State to help us save our son went unheard. When our son's health became critical, we realized Kansas wouldn't move fast enough to save his life. That was three years ago..

In November 2017 our family, life long Kansas residents, were forced to become American Medical Refugees, to save our son Gavin.

I would like to give you a little history about our son, Gavin, and tell you about his success with Cannabis therapies. I hope our journey, our struggles, and Gavin's success, will enact change for desperate Kansas patients, in the immediate future.

Our son Gavin is 11 years old. He suffers from a rare and catastrophic form of epilepsy. Myoclonic Astatic Epilepsy, formerly known as, Doose Syndrome. Categorized as difficult to treat and often drug resistant. For patients who are diagnosed as refractory and are resistant to treatment, the prognosis is extremely poor.

Gavin has 6 seizure types that occur all over the brain, as opposed to one focal area. Myoclonic, Myoclonic Atonic (drop seizure) Atypical absence, Absence, Tonic and Tonic Clonic. Gavin also suffered from various types of status seizures, when seizures occur back to back without any relief between seizures. In Kansas, Gavin would endure from dozens, to hundreds of seizures a day, mixed in seizure types.

Gavin's seizures are generalized. They start in one area of the brain and spread to multiple areas of the brain, causing many seizure types to occur simultaneously. When dealing with seizure types that fire in several areas of the brain, multiple drugs are often prescribed. In Gavin's case, one drug "might" stop one seizure type, but would significantly aggravate his other seizure types. For this reason, doctors prescribed Gavin multiple heavy, psychotropic, anti epileptic drugs in an attempt to stop the seizures. Unfortunately, by doing so, they sedate the brain so much, the ability to learn and grow cognitively, is substantially diminished. Even more so than the seizures themselves. 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 from the drugs meant to help him include; tremors, stomach (digestive) problems, headaches, confusion, drooling, fits of rage, hallucinations, uncontrollable crying or laughing spells, and significant increase in one seizure type or another. The most devastating as a parent, was watching the loss of personality, coordination and severe impairment of cognitive function.

At age 5, Gavin was so heavily drugged he was no longer able to recognize letters, colors, or shapes, he was unable to write anything but scribbles. Pharmaceutical 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 suffered 20 seizures in an hour, mixed in type. 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 multiple AED's (Anti-Epileptic Drugs). All failed to stop his seizures. In fact, they became so frequent that they told me to stop trying to log them; they were just too frequent.

Gavin was given ONFI, Topamax, Depakote, Valium and Lacosamide to try and stop the seizures; powerful, psychotropic, addictive and highly sedating drugs. The seizures persisted. All drugs failed to provide relief. With every addition and increased dose of medications, we watched our child grow quieter. We watched him fade away into a seizing shell of a child. Devastating. After several days we were sent home devastated with another prescription for Felbamate. (It was never filled). Felbamate is an extremely risky drug that includes a black box warning and is known to cause horrific side effects and even death.

Once home, Gavin was unable to walk or talk. He just sat on the couch seizing and drooling from medications. Our son was being drugged to death and we were certain we were going to lose him. Not from the Epilepsy, but from the pharmaceutical cocktail of FDA approved drugs prescribed by his doctors. Also important to note, many of these drugs prescribed have NEVER been studied on pediatric patients.

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. We decided to have it rush ordered. Within hours of his first dose he was able to say "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. After several weeks on CBD, Gavin had his very first seizure free day. Over the course of several months, using industrial Hemp CBD, we slowly weaned one medication at a time. Gavin's cognitive function improved tenfold. We were watching our child come back to life!

The specialists at Children's Mercy Hospital released Gavin as a patient, over our choice to use hemp oil. Even though they could clearly see it was helping FAR more than any of the pharmaceutical drugs. We were able to find a doctor who supported our decisions and helped us safely wean Gavin's pharmaceutical cocktail over the course of several months. With each reduction and removal of each pharmaceutical, Gavin became brighter, he regained his cognitive function and then, the seizures stopped.

We took Gavin to KU Medical Center. His new neurologist with 40 years experience agreed, Gavin suffered severe seizure aggravation and horrific side effects from all pharmaceutical drugs. Even "rescue" medications wouldn't stop Gavin's seizures. He supported our choice to not implement more pharmaceutical drugs and that Gavin deserved quality of life. He also had extensive knowledge of the Endocannabinoid System and was extremely frustrated with the lack of research and access to something non-toxic and proven effective to treat those when traditional medicine fails.

We enrolled Gavin in kindergarten in August of 2014. Just that previous May we didn't think it would be possible for Gavin to attend school with his peers. Gavin had to start over. He had to relearn absolutely everything. Thanks to the removal of the pharmaceutical drugs and the significant reduction in seizures, Gavin was able to relearn most things very quickly.

Gavin remained seizure free until November of 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 would never again have a seizure free day in Kansas. CBD only, would not stop his multiple seizure types. Gavin went 3 ½ years without a prolonged Tonic Clonic seizure. When they returned in October 2017, our family would be divided and forever changed.

Gavin continued to have multiple seizure types over the next several years. He suffered countless injuries and severe cognitive delays. Prolonged absence seizures would cause him to lose bladder control countless times a day. These seizures cause patients to "lose time" creating confusion and memory loss. He had a full time para in school to work with him at his level, and to keep him safe. His teachers and paras would soon learn, keeping Gavin safe, would be next to impossible. His seizures would come without warning and happen as fast as the flip of a light switch. Gavin was having severe drop seizures, causing him to knock out teeth, broken eye sockets, splitting his chin, busting his nose and causing countless facial injuries. You see, a drop seizure is like someone "switching the lights off" in Gavin's brain. Without warning Gavin would lose all muscle tone and his body would slam to the ground, face first. I can not describe the horror we have witnessed our son endure. We HAD to find a way to stop them.

In October 2017 Gavin suffered his first Tonic Clonic seizure in 3 ½ years. Gavin started having repeat nocturnal seizures, which are the most deadly, on top of the other seizure types. Against my intuition, we started his "last option", a drug called Zonasamide. Since Gavin had both seizure aggravation and horrific side effects with all drugs previously used, we started him on a very low dose. Within 24 hours Gavin was suffering almost non-stop seizures, again, mixed in type. He was an emotional disaster! Crying and screaming spells. His speech was so slurred, he was almost impossible to understand. We had no coordination and was a walking danger. His neurologist advised us that removing this drug would be grounds for "medical neglect" and that the side effects we described were "likely not from the drug" but from the epilepsy itself. We

knew with 100% certainty, he was wrong. Gavin had suffered paradoxical reactions from every drug he tried, singularly and in multiple combinations. After researching the drug further, we found that what we were seeing was indeed side effects listed on the warning label. The catch was, this drug (like so many others) had NEVER been studied on pediatric patients.

Gavin was rapidly declining. There was no way we could send him back to school and expect them to be able to keep him safe. We ordered Gavin a special chair that had a 4 point harness to protect him from his constant drop seizures that would slam him face first into his table or anything around him. Gavin wore a helmet 100% of the time. His caregivers at school were also devastated watching our bright, active amazing boy fade away once again. The seizures persisted. Gavin's abilities had diminished rapidly. Again, we had a shell of our child, drooling, seizing and unable to function.

Two days before Thanksgiving 2017, in the middle of the night, Gavin and I got on a train to Colorado. We left behind my loving husband and 3 other boys. Age 6, 11 and 17. It would be several months before we were reunited.

I had no way of knowing this would be the most terrifying night of my life. Gavin seized uncontrollably from the second we boarded the train. I put out an SOS on Facebook, where advocates in Kansas and across the country stayed up all night, searching for a place for Gavin and I to go.

The advocacy community stepped up in every way possible. A Kansas family picked us up from the train station and took us to a hotel in Florence, Colorado. Advocates from American Medical Refugees paid for our hotel and brought us food and medicine for Gavin, who was still seizing constantly.

I was contacted by another family, from Lawrence, Kansas, who are refugees with their 4 year old son, who also suffers from a debilitating form of epilepsy. This family offered to take Gavin and I into their home. They allowed us to rent their fully finished basement so we could establish residency in Colorado and get Gavin his medical cannabis card.

After 2 weeks in Colorado, using the cannabinoid THC-A, Gavin had his first seizure free day in almost 4 years! It wasn't without hiccups. It would take Gavin having access to multiple cannabinoids, to achieve real seizure freedom. Gavin has benefited from the use of THC, THCA, CBN and CBD. Gavin currently uses a 10:1 Ratio of THC to .03% CBD. The exact opposite of what you find in Hemp derived oils, which has no more than .03% CBD. Gavin uses high THC suppositories for Status seizures, edibles to break clustering seizures and a high-THC concentrate for daily maintenance to control his 6 seizure types. Allowing various forms of ingestion is critical for patients with various ailments. No person's Endocannabinoid system is the same. We all receive and process cannabis differently. Each individual is unique. Gavin benefits from multiple cannabinoids with the same thought process when prescribed pharmaceutical drugs. One drug may help one seizure type, but not others. Different

cannabinoids can be applied therapeutically for different seizure types. Who needs what, is entirely individual, which is why any restrictions and limitations of the cannabis plant prohibits patients from getting the relief they need.

When Gavin first started school in Colorado, in March of 2017 he tested at a pre-K level, in the 3rd grade. He was reading about 25 words a minute. Today Gavin is in 6th grade, reading almost 200 words per minute. He doesn't require a para- at all. He is no longer in a safety seat. He only wears his helmet when playing sports or at recess. He has almost caught up to his peers. Gavin was even able to achieve his ultimate dream our first summer in Colorado and play flag football! Gavin can go swimming, ride a bike & learn and retain information! He has independence and self confidence!

Gavin had an EEG when we first arrived in Colorado that showed his brain was constantly seizing from all areas of his brain. It showed spike waves and significant background slowing, which is indicative of learning disabilities and cognitive delays. In August 2018 we did another extended EEG. It showed NO seizure activity whatsoever. ZERO spike waves and significant improvement in background slowing! His neurologist said what this showed was "absolutely remarkable" Gavin's brain is HEALING!!! As of today, Gavin has had just shy of 2 YEARS seizure free, over the three years we have been in Colorado.

Moving to Colorado came with a heavy price. Our family will never be the same. There are the people we were before, and the people we are now. I had only been away from any of my children once, for 72 hours in their lives. I was a stay at home Mom. Suddenly, I was gone... for months. Our leaving was NOT planned. My husband and children were devastated, especially my 6 year old. I can't even describe the pain of being separated from my family. I don't know if we will ever be able to fully heal from this experience. A patient's access to medical cannabis should be entirely between patients and doctors, without limitations to THC percentages or various forms of ingestion.

The financial, physical and emotional strain of becoming AMERICAN medical refugees, is tremendous. It took us almost 4 months to find a home to rent in Colorado. We went from paying \$800 for a 4 bedroom home to paying \$1,500 for rent in Colorado. Insurance rates and basic cost of living is substantially higher. The separation and move in total, cost over \$10,000! Raised by our community! We are forever thankful.

We desperately miss our friends and family, our neighbors, schools and our home. I was born and raised in Stillwell Kansas, and will always be a "Kansas girl" at heart.

We remain committed to ending the prohibition of cannabis in Kansas, and in every State where prohibition of this life saving plant continues. In Colorado we have an abundance of medical refugee families, many from Kansas. Most are not as lucky as we have been, forced to live in terrible conditions, hotels and even their cars. This shouldn't be happening in the United States of America.

Please take immediate action to pass comprehensive cannabis legislation THIS SESSION!
What could possibly be more important than saving the lives and improving the quality of lives of Kansans most fragile patients?

I appreciate your time and attention to this urgent matter. We miss our family, friends and community desperately. We pray the Kansas legislature will enact a comprehensive medical bill this session. No family should have to endure what ours, and countless others have.

We should not have American Medical Refugees, in the United States of America.

Respectfully,

Melissa, Brandon, Dyllan, Caleb, Gavin and Isaiah Ragsdale

American Medical Refugees
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