

To whom it may concern:

In opposition to HB 2152

In support of the Kansas Safe Access Act HB 2348

My name is Christine Gordon. I have a 5-yr. old daughter we call Baby Autumn. Some of you may recognize me as I have been in communication with Topeka for 4 years begging for help for my daughter. We reside in Lenexa Kansas. At 3 mos. old she started to have seizures. After months of EEG's, MRI's, cat scans, and a lumbar puncture, a genetics test told us that she has a genetic mutation called sodium channelopathy SCN-1A. This causes her to have refractory epilepsy, prone to prolonged and febrile seizures. Many of her seizures have triggers such as rise in body temperature, being too upset or excited, fatigue, and illness. However, she has been known to seize without any trigger at all. She has very rarely come out of a seizure on her own. They generally need to be assisted with medication. This genetic mutation also makes her unable to use any antiepileptic medications that affect sodium channels, as they intensify the seizures. Drastically reducing her treatment options. The few pharmaceuticals available to her have not been able to control her seizures. They do however give her side effects including but not limited to, irritability, loss of appetite, insomnia, damage to organs, decaying of her teeth, and cause her to go into respiratory and cardiac arrest. On a regular basis, Autumn is put on life support. We have been told by her neurologist that she has exhausted her options. So much so that we are now being referred to St. Louis for treatment options. Her pediatrician wants her to have the opportunity to try cannabis oil. Her letter of recommendation has been submitted for the last two years and will be submitted again this year for the full spectrum medical bill, SB 187 The Kansas Safe Access Act. As we have tried numerous cbd oils without effectiveness that are **already available to us as per the federal farm act.**

With Autumn's condition being so unpredictable our lives have been rearranged. I can no longer work because I must stay home to care for her. This puts a big financial burden on our family and has caused Kansas tax payers to have to pick up the bill. Autumn is on disability, state insurance, and food assistance. This puts a huge financial burden on taxpayers. With monthly meds, visits to the ER, stays in intensive care, doctor visits, tests, specialists, in home therapies, it adds up and quickly. Kansas taxpayers spend thousands monthly on my daughter's

care. Her daily meds alone cost the state \$4,072.86 A MONTH! Her last emergency room visit cost the state \$8,194.26. Remember we make these visits multiple times a month every month for years. She is now being referred to neurologists in St. Louis, so Kansas tax dollars will be leaving the state due to lack of treatment options here. This is of course not what we want. I would love to be able to go back to work and support my family. As she is not the only one that taxpayers now care for. All 5 of my kids are also on state Kancare due to my inability to work. Though she by far has the most expenses.

Being sensitive to temperature, majority of the spring and summer we can't take her outside (when temperatures reach over 70 degrees.) No more afternoons at the park, camping trips, afternoons fishing, going to the zoo, even taking the dogs for a walk, grocery store trips, etc. The rest of the kids' activities are also limited by her condition. With illness being a huge trigger for Autumn we don't often get out to public places in the winter either. This includes family get together, and often holidays. There have been numerous occasions we have had plans to see family or go to the kids' school events only to have our plans ripped out in an instant. To suddenly need to stop everything you are doing to take an ambulance ride to the emergency room. The feeling of utter helplessness as you watch your most precious gift being tortured with seizures, and all you can do is watch. Each and every seizure could be her last. SUDEP or sudden unexpected death in epilepsy is very real and the chances are much higher for those that are uncontrolled, like our Autumn. We have been fortunate to be able to bring her back home thus far. There were many days that we watched her seize for **hours** and really didn't think we would ever see her beautiful blue eyes again. Then there is the part nobody tells you about, the getting home part. To walk into the house exhausted, battered, and bruised from nights of holding her in chairs, sleeping on hospital floors. To see the furniture pushed away to make room for emergency equipment. Trash and debris left all over the floor from the EMT's trying so hard to keep her with you. Depending on what you were doing before you left it can get really bad when you get back. Like the time we were trying to make homemade corn dogs with the kids for the first time. My husband comes running into the front room next to the kitchen screaming "Chris HELP ME, HELP ME." Holding our baby 6 mos. old) lifeless in his arms. Autumn was blue, distorted, and in distress. Her vitals were very low as she seized. We dropped everything where it was to help this fragile child. We came home to everything

exactly how it was left. We had been gone for days. Six to be exact. The putrid smell of spoiling batter, left out hot dogs, and rotting eggs was horrible, but not as horrible as the flashback of what had just transpired there days ago. This has created a house full of hermits. Hermits with anxiety who are always on edge. With a family of eight this can get difficult to deal with and is completely unfair to the other members.

All our bodies have an endocannabinoid system, yes even yours. The endogenous cannabinoid system, named after the plant that led to its discovery, is perhaps the most important physiologic system involved in establishing and maintaining human health. Endocannabinoids and their receptors are found throughout the body. In each tissue, the cannabinoid system performs different tasks, but the goal is always the same: homeostasis, the maintenance of a stable internal environment despite fluctuations in the external environment.

The endocannabinoid system, with its complex actions in our immune system, nervous system, and all the body's organs, is literally a bridge between body and mind. Cannabinoid receptors are present throughout the body, embedded in cell membranes, and are believed to be more numerous than any other receptor system. When cannabinoid receptors are stimulated, a variety of physiologic processes ensue. Researchers have identified two cannabinoid receptors: CB1, predominantly present in the nervous system, connective tissues, gonads, glands, and organs; and CB2, predominantly found in the immune system and its associated structures. Many tissues contain both CB1 and CB2 receptors, each linked to a different action. Researchers speculate there may be a third cannabinoid receptor waiting to be discovered. Being that the plant has so many cannabinoids, terpenes, flavonoids, components to the plant it has been discovered that the body needs the different compounds of the plant to work effectively. This is called the entourage effect. Cannabis has anticonvulsant properties. This has been known for over a decade. Since cannabis does not work on the brain stem like most pharmaceuticals do, it does not cause patients to stop breathing or the heart to stop like the current medications used on my daughter do. In the thousands of years cannabis has been around there have been zero recorded deaths from cannabis as a first cause. This comes directly from the CDC. This cannot be said about any pharmaceutical including children's Tylenol. It is safer than hot dogs, water, and

vending machines.

Contrary to the thought that cannabis destroys brain cells the US federal government holds a patent on it as a neuroprotectant and an antioxidant. Patent # 6630507. They also have a federal program where they have been supplying patients with cannabis since 1976. The federal government released a spending bill that prohibits them from raiding legal medical cannabis states. This bill has recently been extended. There are even banks and investors stepping up in the cannabis industry. Kansas prides itself on education and health services. It is past time we embrace the education and medical cannabis capabilities.

The first recorded use of cannabis as medicine in Chinese pharmacopoeia was in 2727 B.C. In every part of the world humankind has used cannabis for a wide variety of health problems. In that history, there is **no** recorded history of death by toxicity. This is because cannabis does not affect brain stem responsible for control of heart rate and lungs. **There have been zero deaths recorded in the history of time for overdose on cannabis.** This cannot be said about the pharmaceuticals that these children are exposed to daily.

Following the patients, physicians, and caregivers in legal states closely. I have learned straight from their mouths (or fingertips) through support groups, websites, and medical studies that the worst part is after finding the strain of cannabis that helps them or their child, they then must wean off the pharmaceuticals they are addicted to. This in itself can be life threatening. This is where physicians, patients and caregivers find that the ability to adjust ratios of the plant are **vital**. To help their bodies survive withdrawal they often need to increase or decrease different components of the plant. Therefore, the Kansas Safe Access Act, a full spectrum bill, is a must. The Kansas Safe Access Act currently sits in your committee. The same can be said for children going through puberty and women going through menopause as their bodies are changing. Just as with other medications adjustment is needed.

Because of the Kentucky farm act added to the federal farm bill, enacted in 2014 states have the right to once again grow hemp and produce hemp products. Thus, we already have access to cbd only supplements and putting forth a hemp bill would be a waste of valuable time and taxpayer money that we do not have.

Being such a large family and having ties to our home and requirements of us by the state, we are unable to relocate. I feel a patient should not have to relocate to use a non-toxic course of treatment **recommended by their physician** without fear of prosecution. Again, copy of our doctor's recommendation is included. I also feel that politicians, and lawmakers should not be burdened with this decision. This decision should be between the patient and their doctor. I ask that we restore that relationship. I demand that we allow these children and patients suffering a safe, non-toxic, option of treatment. I hope that you can hear my desperate cry for help to treat our beautiful little angel who has so much potential. Whom should not have to suffer another year needlessly. You have the power here to help save lives. What if it were your child?



12/05/2016

**To Whom It May Concern:**

Autumn Gordon was a patient in the Heartland Primary Care-Lenexa practice on 12/05/2016. Autumn may return to work/school with the following restrictions: she has SCN-1 gene mutation causing severe refractory epilepsy -- I recommend home services for her continuing education needs due to length of seizures with rescue medications needing to be given within the first several minutes of seizure starting in order to decrease duration of seizures

If you have further questions regarding this patient's health status, please contact us at (913) 299-3700.

*G. Black DO*

Gretchen Black DO