

To whom this may concern:

My name is Christine Gordon. I was a lifelong Kansas resident until 2 ½ years ago. My youngest of 5 children is diagnosed with Dravet Syndrome epilepsy and severe autism. Dravet syndrome is a rare, catastrophic, lifelong form of epilepsy that begins in the first year of life with frequent and/or prolonged seizures. Previously known as Severe Myoclonic Epilepsy of Infancy (SMEI), it affects 1:15,700 individuals, 80% of whom have a mutation in their SCN1A gene [1]. While seizures persist, other comorbidities such as developmental delay and abnormal EEGs are often not evident until the second or third year of life. Common issues associated with Dravet syndrome include:

- Prolonged seizures
- Frequent seizures
- Behavioral and developmental delays
- Movement and balance issues
- Orthopedic conditions
- Delayed language and speech issues
- Growth and nutrition issues
- Sleeping difficulties
- Chronic infections
- Sensory integration disorders
- Dysautonomia, or disruptions of the autonomic nervous system which can lead to difficulty regulating body temperature, heart rate, blood pressure, and other issues

Current treatment options are limited, and the constant care required for someone suffering from Dravet syndrome can severely impact the patient's and the family's quality of life. Patients with Dravet syndrome face a 15-20% mortality rate due to SUDEP (Sudden Unexpected Death in Epilepsy), prolonged seizures, seizure-related accidents such as drowning, and infections.

At 3 mos old Autumn began to have prolonged seizures that could last hours at a time. 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 and treatment options 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, multiple times a month, Autumn was put on life support. We were told by her neurologist that she had exhausted her options in Kansas. So much so that we were now being referred to St. Louis for treatment options. Her Kansas pediatrician wanted her to have the opportunity to try cannabis oil. Her letter of recommendation has been submitted for multiple years. Our community very much supported Autumn having the opportunity to try cannabis. From her pediatrician, neurologist, EMT, fire rescue, neighbors, and family.

We tried numerous hemp cbd oils without effectiveness that were already available to us as per the federal farm act.

With Autumn's condition being so unpredictable our lives had been rearranged. I could no longer work because I had to stay home to care for her. This put a big financial burden on our family and caused Kansas tax payers to have to pick up the bill. Autumn was on disability, state insurance, and food assistance. We often had to get help with utilities as well. This put 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 spent 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 made these visits multiple times a month every month for years. She was referred to a neurologist in St. Louis, so Kansas tax dollars left the state due to lack of treatment options here. This is of course not what we wanted. I would have loved to be able to go back to work and support my family. As she is not the only one that taxpayers now had to care for. All 5 of my kids were also on state Kancare due to my inability to work. Though, she by far, had the most expenses.

Being sensitive to temperature, for the majority of the spring and summer we couldn'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 were also limited by her condition. With illness being a huge trigger for Autumn we didn't often get out to public places in the winter either. This included family get-togethers, and often holidays. There were numerous occasions we 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 was. We were 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. Waiting for the next emergency. The next crash. The next disappearance. With a family of eight this can get difficult to deal with and is completely unfair to the other members. Both dad and I had developed PTSD from watching our child in trauma for so many years. Despite our best efforts Kansas just kept giving our baby a death sentence.

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 pharmaceuticals used on my daughter did. 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 the 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 learned straight from their mouths (or fingertips) through support groups, websites, and medical studies, then experiencing it for ourselves, that the hardest part is after finding the strain of cannabis or products that help 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. 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.

After 6 years of pleading with legislation to help our child who was deteriorating before our eyes, we made the impossible choice to relocate. Autumn was a shell of a child. She was often described like an angry, screaming, zombie. She could not talk. She had difficulty walking. She was very self injurious and often had to wear a helmet and be locked into an adaptive stroller for her safety and others. She was a 7 yr old that was at the developmental level of a 1yr old requiring non stop care. I had to feed her, change her (incontinent) , regulate so many harmful pharmaceuticals, constant cleaning and safety precautions. I was completely exhausted and completely out of hope.

I went back to school and did fast track courses to change my career field so I could work in Colorado. We started a go fund me and put on multiple fundraisers to get this child out of a state that did not have a heart for patients like her. We packed what we could fit in a truck and left the rest behind. This was not limited to possessions. We LEFT OUR EVERYTHING! Our family, our friends, our community, even some of my children. The feeling of pulling away from my home in that U-haul with my mom, my best friends, and my children being left behind. There are NO words to describe that feeling. I was shattered in a million pieces. I was scared. I did not know if I would ever see them again. I did not know the incredibly difficult and lonely road I was about to walk. I shortly had to pull that truck over. I was crying so incredibly hard that I could not see to drive. That was only one of several stops I would make to cry and collect myself. Thankfully 2 of my children were in my husband's car so they did not know. I packed our dogs in the truck with me to make the 10 ½ hour drive.

We have now been in Colorado for 2 ½ years. Autumn has been a legal cannabis patient for 2 yrs. She is allowed to take her medicine anywhere she goes. Not only are we using cannabis for daily control of seizures and behavior, but we also use it as a rescue for the much fewer seizures that come up. Being able to keep her medicine with her has been imperative and amazing. Being her legal caregiver I don't have to worry about being prosecuted while traveling and administering her cannabis. Protection for patients and caregivers is a must. We have access to a variety of products with different delivery methods. This has made such a HUGE difference in the quality of life for Autumn. Depending on her needs we can adjust her medicine and convenience. Autumn regularly uses edibles, topicals, and tinctures. If she is having a bad day being able to eat I can use other delivery methods to help her. Since being on cannabis Autumn has seen a 90-95% reduction in seizures. She has not been admitted to the emergency room in over a year. We have been able to wean almost all of her pharmaceuticals. We have one left to go. She has been able to gain skills physically and developmentally. This former zombie of a child can now do more than I ever imagined possible. Last year for the first time in her life I got to hear the words "mommy I love you" for the first time ever. That right there made all of the heartache, sacrifice, and work worth it. It doesn't stop there. Autumn is able to walk much more efficiently.

She can talk in sentences and hold conversations. She writes!! Yes Autumn can write words now. She can cook several simple meals with supervision like eggs, pancakes, spaghetti, etc. She knows her alphabet, colors, animals, feelings, and is beginning basic math. She is able to do much of her activities of daily living on her own when before she was completely dependent on others for care. She can dress herself, brush her teeth, bathe with supervision, and has even begun potty training. Her behavior issues and self injurious tendencies are very few and far between. She tries to elope much less making her safety easier to maintain. They are also much less intense. She very rarely injures others anymore. I am so very grateful for that. We are absolutely blown away by her progress in such a short time but, it doesn't stop there. Because Autumn is doing so much better and Colorado has cannabis funding for programs, our family is thriving as a whole. I am able to work again. I have not only been able to support my family but I was able to increase my non existent credit and buy my first home. This way I can make the modifications to our home that Autumn may need as she grows. My other children are back in my care and happy again. The household dynamic has changed as a whole. We have much less anxiety and stress. We were, until covid, able to get out and do things with the public. We are no longer shut ins that were shunned from living life. We learn, love, and grow. We hike in the mountains. We support our community. We pay our taxes. I have not been on public assistance in over 2 yrs.

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. 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 will take our success story to heart and give patients still suffering in Kansas an opportunity for quality of life. Who should not have to suffer another year needlessly. You have the power here to help save lives instead of handing out death sentences. What if it were your child?

With great pride,

Christine M Gordon

