

STATE OF KANSAS
HOUSE OF REPRESENTATIVES

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JOHN WILSON
10TH DISTRICT

February 17, 2015

Chairman Hawkins and Members of the Committee:

On behalf of my constituents and hundreds of Kansans living with debilitating seizures, I stand in strong support of HB 2282 – Otis’ Law.

Otis’ Law is a limited high-CBD, low-THC medical hemp bill designed to allow regulated access to products which contain the active ingredient cannabidiol, or CBD. CBD is one of over 60 compounds found in the plant Cannabis sativa L. belonging to a class of molecules called cannabinoids. **CBD has no intoxicating effects.** THC, or tetrahydrocannabinol, is the chemical responsible for most of marijuana's psychological effects. CBD and THC levels tend to vary among different plants. Marijuana grown for recreational purposes often contains more THC than CBD. However, by using selective breeding techniques, growers have created varieties with high levels of CBD and almost no THC.

HB 2282 differs significantly from the “medical marijuana” bills that have been introduced over the past few years in the Kansas Legislature, including HB 2011, which was introduced this session. This bill represents a Kansas solution—a solution that is designed for very specific medical conditions and with very limited forms of consumption and access.

With that in mind, I think it’s important and helpful to understand what this bill doesn’t do.

HB 2282...

- Does not allow the growing or consumption of marijuana with any intoxicating or psychoactive effects
- Does not allow for recreational use of marijuana
- Does not allow people to grow marijuana at home
- Does not allow all (or even-most) medical conditions to be treated with marijuana
- Does not legalize “industrial” hemp
- Does not decriminalize marijuana possession
- Does not allow for shipping or sending marijuana by mail or other shipping service

So if that’s what the bill doesn’t do, what does it do?

Under HB 2282...

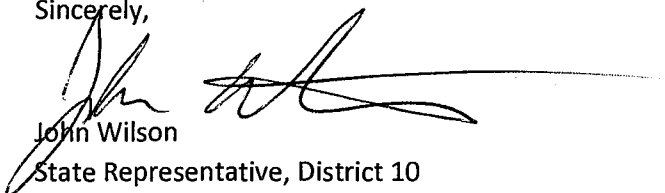
- A patient with a qualifying condition would have legal access to hemp products with no more than 3% THC (not enough for impairment)
- A patient must have doctor-issued certification in order to be eligible
- A patient could have one designated caregiver, who must register with the health department.
- Licensed producers would cultivate state-compliant varieties of hemp, perform extraction processes, and meet packaging and labeling requirements established by KDHE
- KDHE would register, regulate and inspect private producers of medical hemp and hemp products
- KDHE would license and regulate independent testing labs

For a detailed analysis of this bill, please reference the handout **“Otis’ Law – Kansas’ Hemp Oil Bill.”**

In the past year, eleven states have passed CBD or hemp oil laws that are unlikely to result in functional state programs for patients due to the type and number of restrictions. The carefully crafted components of Otis’ law balance the need for positive health outcomes with the need to protect public and patient safety. Furthermore, Otis’ Law provides a regulatory framework for any forthcoming changes that may occur as a result of changes at the federal level. Until that time, I think we should be doing all we can for Kansans searching for help.

If Otis Reed and Owen Klug were the only ones to benefit from the passage of HB 2282, I wholeheartedly believe that it is still worth our time, effort and consideration. I hope you will join me in supporting the passage of Otis’ Law out of committee and in sharing the stories you heard today with the rest of our colleagues in the House.

Sincerely,



John Wilson
State Representative, District 10

Oral testimony for House Bill 2282

Presented by:

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Good afternoon respected members of our House Health and Human Services Committee. My name is Kiley Klug and this is my son Owen, who is a happy, laid back 7-year-old. My husband Gavin and I have two sons at home, Dexter, who is 4, and Blake, who is 1.

Owen has been on quite a journey in his brief 7 years of life. He was brought into this world to us after a completely normal pregnancy and childbirth. Owen was developing normally and thriving until six months of age. I remember the phone call from my husband like it was yesterday. I was on my way to chaperone a middle school dance. Gavin was frantic. He was feeding Owen, and I remember him screaming, "Kiley, something's wrong. Owen's eyes are rolling to the back of his head. I think he's having a seizure." Everything changed in that one pivotal moment in our lives.

We spent the next four years in hospitals and clinics while they administered genetic testing and diagnostic procedures to determine what was causing Owen's seizures. Owen began significantly falling behind developmentally as well. The seizures would come and go, and his development would follow suit depending on the seizure frequency at the time. By his second birthday, Owen was having multiple seizures daily. He endured MRIs, EEGs, CT scans, spinal taps, surgeries, extensive genetic testing, and trips around the country to top neurological specialists. A video EEG conducted when Owen was three years old showed he had over 200 seizures in an 18-hour period. At the age of four, Owen was diagnosed with Dravet Syndrome. Since then, we have tried everything including: a combination of 8 different pharmaceutical medications, acupuncture, a ventricular nerve stimulator (VNS), oil therapy, special diets including but not limited to the ketogenic diet, and other various wholistic treatments, for example cranial-sacrum. We have tried everything available to us in the current situation we are in. Gavin and I believe we have religiously, almost to a fault, followed Owen's doctors' recommendations. For example, at one point Owen's neurologist had him on both the ketogenic diet and four pharmaceutical medications. Owen was so incoherent that he couldn't even focus to eat his food. I would spend literally an hour shoving the carefully measured out food down his throat, only to have him vomit it up in the end. Owen regurgitated three meals a day for three months before his doctor hospitalized him and immediately cold-turkey weaned him off of two of the four medications.

Unfortunately, after everything we have tried, Owen continues to seize an estimated 10-40 times a day....and that number only includes the seizures we visibly see. I think it's important to note that Owen's development hugely relies on seizure control. His development is a roller

coaster; one month he will be able to sit independently for 30 minutes at a time, and the next month he cannot sit for more than ten seconds. He used to walk in a walker, hold his own cup, and babble "mama" and "dada." I can't even convey how difficult it has been to watch our son decline and struggle. However, on a positive note, once his seizures are even remotely controlled, he could possibly begin to communicate and become more mobile. Owen's developmental future is an open book. I'm standing here today asking you to write the next chapter, and that chapter involves Owen gaining access to cannabis oil in the hopes that his seizures would be at least decreased if not controlled.

Committee members, I am respectfully by all means in support of whole-plant medical-only legislation. However, I realize that the Kansas government is ready for neither SB9 nor HB2011 at this time. And at this time, I am ok with that. As Owen's mother, I am asking you to consider this compromise bill of HB2282. This bill would at least allow Owen to legally access three or four strains of high CBD oil to try, yet is restrictive enough to ease the hesitant mind at this time.

I cannot stress enough that Owen has nothing else to try in this state. Please allow him access to a natural, safe, non-hallucinogenic medication that could give him a chance to be present in this life.

We both grew up in Kansas, and Kansas will always be our home.

After college, we met and moved to New York City. After becoming engaged a few years later, we made a decision to start our lives together as a married couple, and to begin our own family, in Kansas, near to our own families.

Upon moving back to Kansas in 2007, Ryan began teaching at a rural high school near Topeka, and Kathy worked at the University of Kansas. We are both hard working, community-minded citizens.

In June of 2011 we had the absolute joy of welcoming our son and only child, Otis, into the world.

In September of 2011 Otis had his first seizure, and Otis received the diagnosis of Infantile Spasms, a catastrophic form of infantile epilepsy. Since that day, the seizures have only progressed, and our own lives have become geared toward stopping those relentless seizures.

Otis has hundreds of seizures a day. These seizures have left him developmentally disabled and completely dependent on us in every way, even in the most basic activities of daily living. The constant seizure activity has prevented Otis from being able to learn, develop, and reach milestones like most typically-developing kids. Although Otis is 3 and-a-half years old now, his developmental level is that of a 6-11 month old, at best.

Otis has been seen by neurologists and epileptologists in Kansas City, St. Louis, the Cleveland Clinic, and Denver. He has tried over a dozen different medications in order to stop his seizures. None of them have provided any seizure relief. In fact, most of these pharmaceuticals have caused negative side effects, from sleeplessness, anorexia, impaired cognition, zombie-like "stoned" states, and severe agitation and rage, to a life threatening cardiomyopathy. In 2013 he had surgery to implant a device, a vagal nerve stimulator (VNS) that would give him shock therapy around the clock. He has also suffered through a very strict diet for 2.5 years that, in combination with the mineral-leaching anticonvulsant pharmaceuticals, left his bones weak, leading to a fractured femur at 2.5 years of age.

Nothing worked to control Otis' seizures, or give him a better quality of life. In fact, it began to seem as though these treatments were working against him.

Our day to day was living seizure to seizure. Days were peppered with seizures and frustration, and nights seemed to be never-ending. Otis did not have a bedtime, and not for our lack of trying. Due to the frequency of his seizure activity, he would fall asleep at 7pm one night and 2am the next night, and naps were few and far between. Most of his seizures came in clusters at night. He would be asleep for 2-3 hours and wake up with a cluster of seizures that usually lasted about an hour, then go back to sleep for an hour or so only to be up again for another hour of seizures. This continued throughout most of the night, every night. There is nothing we have experienced more heartbreaking than helplessly holding our child night after night as he seizes uncontrollably.

Our team of neurologists told us that, having been failed by all else, our last option was to remove or disconnect half of Otis' brain. Because EEGs, MRIs, and a PET scan have not been able to identify a focal point in Otis' brain where the seizures are originating, his seizures are considered to be generalized, meaning that they appear to come from all over his brain. Because of this, the hemispherectomy surgery is seen as a last resort. Surgery is not only a risky and permanent last resort, but the chances of success are not good—less than 50% chance of any seizure improvement at all, for a child who suffers over 500 seizures each and every day. Those odds are just not good enough for our son. We agreed with our doctors, brain surgery would be a last resort.

In the fall of 2013 we began to hear about how medical marijuana has helped children with severe, drug-resistant forms of epilepsy like Otis. At first we were skeptical, but after talking to some of these parents we knew that we had to try medical marijuana before we removed half of our son's brain.

Our options at this point were: 1. Permanently cut out half of our child's brain with no guarantee of success, short or long term, or 2. Try a medicinal plant that has worked well for other children like Otis.

We decided to try medical marijuana.

The decision was easy; however, the act of providing this medicine to our son was far from easy. In order to give our son a chance at a better quality of life we gave up our home, our jobs, our support system, and being close to those we love.

Because of current laws in Kansas--our home--we had to uproot our lives and move to another state, Colorado, on the hope that medical marijuana would help Otis. It was difficult and continues to be difficult to be so far from our home and the ones we love, but we would do it again in a heartbeat to provide a better life for our son.

Since beginning high CBD, low THC medical marijuana treatment, Otis' quality of life has greatly improved. He now has a regular bedtime of 8pm and sleeps anywhere from 4 to 9 hours *in a row* for the first time in his life, which has helped us all. Over the course of the 8 months he has been on the CBD treatment, we have been able to wean him over half way off of his remaining anti-epileptic drug, a benzodiazepine called ONFI (or Clobazam), known to be more addictive than even heroin. He has improved cognitively and developmentally. He has learned to drink from a straw, assist in sitting up and standing, assist in feeding himself, army crawl to a desired object, and use his previously unused right hand...just to name a few. He has become clearer and more alert, making more eye contact, interacting more with us, his therapists, and his peers at preschool. He now giggles and reacts to being tickled. He continues to become stronger and stronger, weight-bearing on his legs and left hand. And the best thing of all...he smiles and laughs each and every day now! All of this without the negative, and many times dangerous, side effects he suffered from the 12 FDA-approved "safe" anticonvulsant medications, steroid therapies, and ketogenic diet that had been prescribed to him—and failed him--previously.

Unfortunately, despite the many and growing cognitive and developmental gains we have seen over the course of the past several months, Otis has not yet experienced the seizure control that many of his new friends out here in Colorado have experienced. Fortunately, there are still many more medical cannabis options available for us to try, and in this, we have been given a renewed sense of hope for Otis' future. Otis is experiencing a better quality life than he has ever experienced, and it is thanks to medical marijuana.

We are dealing with a difficult diagnosis for which there is no cure. Our day to day is hard, but we are managing...and managing well, we think, despite the many obstacles with which we are faced. But to add to the mix a move away from our home, our families, and our support system...it's not right. As parents of a child with severe special and medical needs, we've got enough work cut out without also having to start our lives over in a new place. We love Kansas, but there is no justice in this. We should be allowed to live in our home and be around the people that we need most during the most difficult trial of our lives. It. Is. Not. Right.

We ask for compassion. We invite you come spend time with us. We welcome you to sit with us as we hopelessly hold our child as he seizes...and see why anyone in our situation would do the same.

We ask you to please imagine, if you can, being in our shoes. As a parent, imagine being told by your child's doctors that they have tried everything, that nearly all medical options except for a very risky brain surgery—one that has, at best, a 50% chance of providing any relief at all--have been exhausted, that there is next to nothing left to be done to heal your child, who is not even 3 years old.

Imagine the fear and absolute desperation you would feel in that situation. Imagine what it is like to sit up with your child, at midnight, 2 a.m., 4 a.m., holding him close to you, helpless as he seizes over and over and over again. Crying, praying, cursing, whispering, hushing, and singing to your child, absolutely helpless, between your own barely contained sobs.

Please ask yourself what you would do, having exhausted all available medical options. Who would you turn to for help? Would you just throw your hands up, toss in the towel and give up on your child? No, you wouldn't. Of course you wouldn't.

You would continue to fight for your child, endlessly, relentlessly, through fear and anger and sorrow and exhaustion, doing everything and anything possible, pursuing anything that offers the slightest possibility of relief for your child. Because if we parents don't fight and advocate for our children, who will? We truly believe that if put in our shoes, any other parent would do the same for their child.

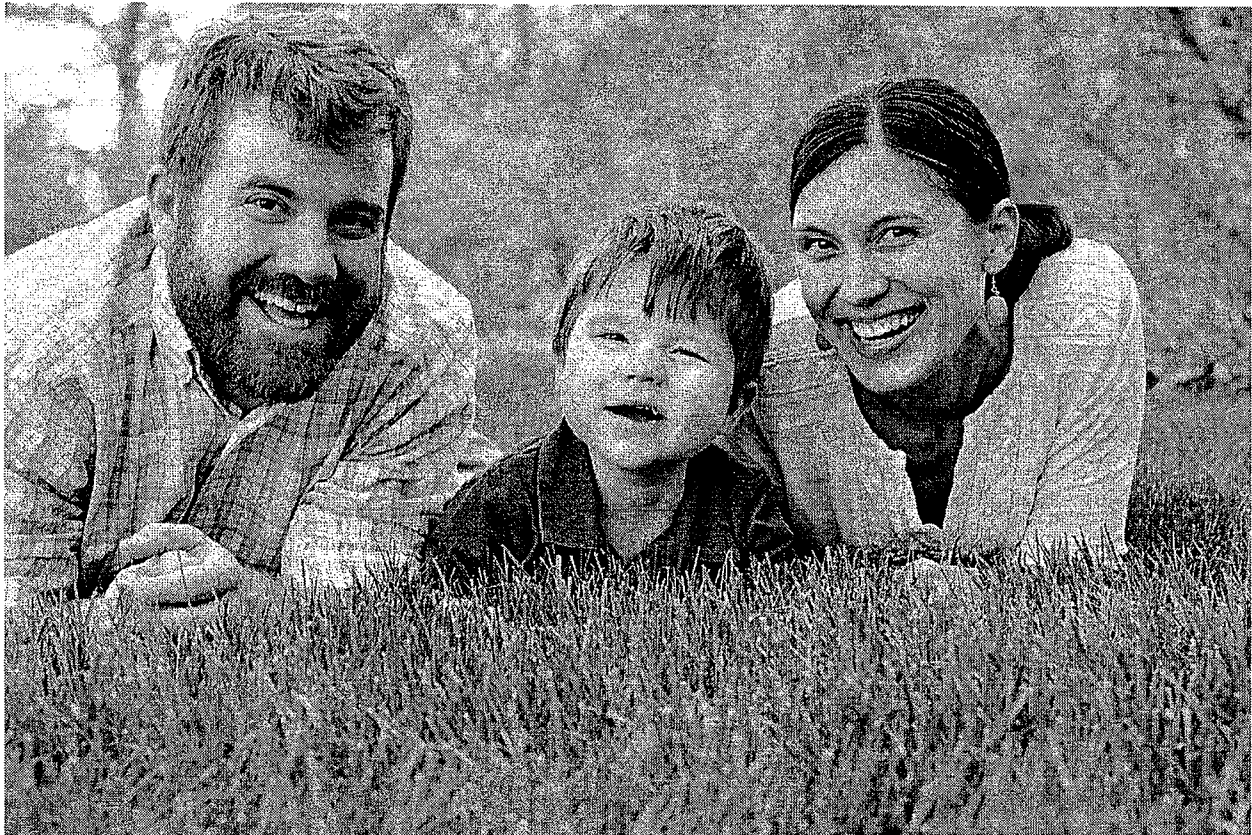
It is our hope and plea that the individuals with the most power and the most influence within our state will have the courage to stand up and do something to help our son and other children in Kansas like him, because we are far from being the only ones—to hear our stories, to have empathy and compassion for these medically fragile children, to give us another option when all else have failed us.

As native Kansans and parents of a child who suffers from progressive, drug-resistant epilepsy, we ask that our Kansas legislators have compassion for our family, for our sweet son Otis, and for other Kansas children like him. It is our hope that Kansas legislators will develop a well-regulated medical marijuana program that allows for research, local cultivation and testing of this promising, plant-based medicine, direct access for patients in need. If nothing else, we ask simply for reciprocity for families like ours, so that we may legally cross the state line into Kansas, with our son's medicine, to visit our families without fear of being prosecuted.

We thank you for hearing our story.

We would be happy to answer any questions you may have about Otis our experience.

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"We change laws."

History and Federal Law Enforcement Policy on Medicinal CBD Laws

Background

In 2014, 11 states enacted laws that were intended to allow patients access to one of several active components of the marijuana plant — cannabidiol, or CBD.¹ This particular compound has received a great deal of recent attention, and there is a substantial amount of anecdotal evidence that it can significantly reduce both the frequency and severity of seizures, including those experienced by minors.²

Laws that establish regulated access to CBD are often referred to as “high-CBD” laws. These laws are designed to provide a framework for cultivating and processing plants rich in CBD, which can be extracted and provided to those who qualify medically. These systems are also designed to significantly limit one ingredient in particular, tetrahydrocannabinol, or THC. While THC has significant medical qualities,³ unlike CBD, it can lead to impairment.

Unfortunately, with very few exceptions, the laws passed during 2014 were unworkable, and without significant changes, these laws are unlikely to result in functional programs for those seizure victims they were intended to help.⁴ While the Marijuana Policy Project advocates for comprehensive medical marijuana programs like those passed in nearly two dozen jurisdictions, we believe it is important that those states that choose to implement high-CBD laws establish workable programs. Simply put, while high CBD laws may help only a fraction of those who benefit from broader programs, they should function well for those whom they serve.

¹ Alabama, Florida, Iowa, Kentucky, Mississippi, Missouri, North Carolina, South Carolina, Tennessee, Utah, and Wisconsin

² Sandra Young, Marijuana stops child's severe seizures, CNN, August 7, 2013, <http://edition.cnn.com/2013/08/07/health/charlotte-child-medical-marijuana/>

³ THC is the only component found in marijuana that has been recognized by the federal government as having medical value, and is provided in synthetic form as an FDA-approved prescription medical called dronabinol, available under the brand name Marinol®. Unfortunately, since THC is the primary component used to treat serious conditions such as cancer, Crohn's disease, multiple sclerosis, and conditions that result in severe pain, the vast majority of patients that could benefit from comprehensive medical marijuana programs are left behind in high-CBD law states.

⁴ Largely this is due to oversights or requirements within those laws that create significant legal hurdles that, while likely well-intentioned, render the law incapable of being implemented. For instance, many high-CBD laws require colleges or universities to cultivate cannabis, placing federal funding for school programs and research in serious jeopardy, or they require physicians to distribute Schedule I substances to patients, or write prescriptions for marijuana-based products, which would require physicians to violate federal laws. These types of provisions are unworkable requirements.

Regulatory Framework

Hemp, marijuana, and cannabis are terms that all refer to the plant *Cannabis Sativa L.*, which the federal government considers to be a Schedule 1 controlled substance, along with the compounds produced naturally in the plant. “Hemp” typically refers to varieties of the plant which contain very small amounts of THC, so the term is well-suited to describe plants used pursuant to high-CBD laws.

Several prominent medical organizations have called on federal authorities to re-classify marijuana so that more research can be conducted. These groups include, most recently, the American Academy of Pediatrics⁵ and the Epilepsy Foundation.⁶ However, the federal government has so far refused to take action. As a result, research has been limited in the U.S. despite the compelling anecdotal evidence that naturally-occurring THC and CBD contain strong medicinal qualities — particularly when used in combination.⁷

Because of the strong interest in this medicinal value, many states have implemented their own regulatory frameworks providing access for seriously ill patients. The federal government has adopted a policy articulated in a Department of Justice memorandum issued to federal prosecutors on August 29, 2013, with respect to state laws.⁸ The cornerstone of this policy is its emphasis on state regulation. Deputy Attorney General James Cole made clear that states that allow access to these products must implement a strong regulatory framework.⁹ Most states that have successful programs have created systems similar to those established in HB 2282.

A well regulated, functional high CBD program for Kansans

Lessons learned so far in the 23 states and the District of Columbia, which have comprehensive medical marijuana laws, and in the 11 states with high-CBD laws are brought to bear in HB 2282, which has adopted best practices for each of these other state laws. It provides seriously ill patients reasonable access to CBD-based medicine, yet takes into account both the limitations imposed under existing federal law, and the specific policy interests outlined by federal law enforcement authorities to fashion a well-regulated system for Kansans.

⁵ <http://aapnews.aapublications.org/content/early/2015/01/26/aapnews.20150126-1>

⁶ <http://www.epilepsy.com/article/2014/2/epilepsy-foundation-calls-increased-medical-marijuana-access-and-research>

⁷ While the federal government has approved pure, synthetically produced THC for use as a prescribed pharmaceutical medication, there is evidence that THC and CBD are most effective when used together. In particular, CBD appears to have its greatest effect when at least trace amounts of THC are also present, even if there is not enough THC to result in impairment. This phenomenon is referred to in scientific literature as the “entourage effect,” and has been the subject of study. See E. Russo, “Taming THC: potential cannabis synergy and phytocannabinoid-terpenoid entourage effects,” *Br J Pharmacol*. 2011 Aug; 163(7): 1344–1364, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3165946/>.

⁸ James M. Cole, Guidance Regarding Marijuana Enforcement, United States Department of Justice, Office of the Deputy Attorney General, August 29, 2013.

<http://www.justice.gov/iso/opa/resources/3052013829132756857467.pdf>

⁹ The memo states, “The Department’s guidance in this memorandum rests on its expectation that state and local governments that have enacted laws authorizing marijuana-related conduct will implement strong and effective regulatory and enforcement systems that will address the threat those state laws could pose to public safety, public health, and other law enforcement interests.”

Our whole family agrees that Kansas should legalize medical marijuana. A few years ago, we wouldn't have agreed with that statement at all. But 2 things changed that--Otis and Education.

Otis has captured our hearts completely. Like any grandparent, we adore our grandson! His smiles brighten our days. However, unlike most grandparents, we have watched Otis have multiple seizures--hundreds per day. It breaks our hearts that he has to suffer. Our hearts also break when we watch our son and daughter-in-law experience this daily. Their new "normal" is not anything like our normal days as parents.

Because of Otis, we have learned about Infantile Spasms and epilepsy. We've also been educated about the Ketogenic Diet, Vagus Nerve Stimulators, and the more than a dozen different medications that he has taken. All of these have failed our little Otis, and several gave terrible side effects that no one should have to experience.

Over a year ago we started reading about medical marijuana helping children with seizures. There was not a moment of hesitation in our minds that Otis needed to try this. We've watched his little body as he seizes, and the crying that sometimes follows breaks our hearts. He doesn't understand what is happening, and neither do we! Sometimes he looks up at us during a seizure as if to say, "Please help me!" After learning about medical marijuana we became hopeful that it could do for Otis what it was doing for Charlotte Figi, or many of the other children that have been helped from taking Charlotte's Web, a form of medical marijuana.

We love this sweet little boy, and we were so glad they lived close by. When Ryan and Kathy told us their plan to move, we were excited about the possibilities. We were saddened that Ryan had to leave his teaching career, and the many Kansas students that will never be able to experience his ability to help kids learn and grow. While Kathy got to keep her job and work remotely, we knew it wouldn't be long before she would also have to leave a job she had come to really enjoy. Through our broken hearts, however, we knew they would need to leave Kansas in order to pursue the medical treatment that might help Otis.

We used to think medical marijuana was just marijuana that was used for medical purposes. We know better now. The medical marijuana that Otis is now using does not make him high, but most definitely has improved his quality of life. He smiles more often, is using the right side of his body more, and has been "army crawling." In many children with epilepsy a reduction of seizures has been seen. We rejoice with these families on the success they have seen, and remain hopeful that we will see fewer seizures for Otis as they find the right strain and dosage for him.

Governor Brownback included the importance of family in his State of State speech, and yet families are being torn apart when they have to make a decision-- "do we go to a state that allows this drug which might improve my child's health or stay in Kansas?" What would YOU do? Being parents of a disabled child is a struggle and a challenge,

without having to uproot the family from relatives, friends, jobs, physical therapists, occupational therapists, schools and other support systems.

Rarely do we take a trip to the grocery store, the post office, our church or a committee meeting that at least one person doesn't ask about Otis. In all of the hundreds of conversations I've had with people, no one has ever questioned why Ryan and Kathy would give Otis medical marijuana. Many of these people are Senior Citizens. They all agree that if they were in those shoes, they would do the same thing. We all simply want the best for Otis.

As life long Kansans, we will be moving to Colorado in order to help Ryan and Kathy with the daily care for Otis. They are the most amazing parents I've ever known; I don't know how they do it, but we want to be able to help them. We will be leaving our son, Taylor, and many other family members, and friends. We built our home over 25 years ago, and have been an active part of our church and community for longer than that. We love Kansas, but will move to Colorado where the medical and funding opportunities support the needs of our grandson.

We would like to see the laws in Kansas change, so that medical marijuana is legal and available for those who need it most. We not only want this to happen for our grandson, but also for the many others who could benefit as well. Please let Kansas be a state of hope for families and not a hindrance.

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I stumbled into the world of medical cannabis research. I came across a video of an accomplished scientist, trapped in a body frozen by Parkinson's. I always remember his eyes. So full of intelligence and vibrancy, and seemingly desperation. He could not walk, talk, swallow or communicate. I cannot imagine such a fate. Then the video showed him, walking, talking, eating a sandwich and at the end, driving his car. I was mesmerized. What caused this amazing symptom alleviation? Medical cannabis.

I was incredulous, at best. So, I did what I do best, research. I opened an overwhelming trove of clinical research from around the globe, including 50 years of research from our ally Israel, and it changed my life. I reached out to my fellow Kansans and began the journey to what is now Bleeding Kansas. So, named by this history geek as a way to honor a proud heritage of compassion and courage that led Kansas to act upon a moral duty. This is how I see the struggle for medical cannabis, our moral duty to our neighbors.

Cannabis should only ever be a patient focused, public health issue. Although, financially beneficial at a time when Kansas is truly desperate for new sources of revenue, I do hope compassion can be our motivation. If you need to hear from patients, we have hundreds of parents, families and patients in our group who would be willing to speak to you about their illness and what a difference this bill could make in their life. This medicine can save thousands of Kansas lives and earn Kansas millions of tax dollars. It is time for Kansas common sense to prevail over fear, misinformation and stigma.

We are asking that as you consider and review this bill that you do not throw baby out with bathwater. If there are questions or concerns that we may instead see those as opportunities to start a collaborative dialogue as we work toward building a great law for patients and for Kansas. Kansas patients have waited too long already. We have lost children and adults during this wait. We, frankly, are tired of grieving what we see as needless deaths, filled with needless suffering. Whatever needs to be addressed, let us address it and move toward relief for patients. This bill does not answer all the needs of Kansas patients by far. We see it as a beginning point. Once it is established that the Kansas sky will not fall if patients receive medicine, and once Kansans begin to heal and patients and their physicians share their stories, leaders will see that cannabis is as equally non-toxic to a conservative career, as the plant is to the human body.

I have much more to share with you, in regards to policies, models and strategies I feel must be addressed in a Kansas law. For now, I will let the patients stories speak to you. I will let the medical research speak to you. And I will hope to speak with you soon about all the ways, fiscal included, that I believe this bill will benefit Kansas patients and Kansas. Thank you for your time today. We appreciate your listening to the voice of patients. If you have any questions, please feel free to contact me.



At one point in America's history, cannabis was medicinally prepared in pharmacies throughout the country—used in one third of all medicines from 1830 – 1930. Following the creation of the Federal Bureau of Narcotics and the subsequent adoption of the Uniform Narcotics Act during prohibition, states quickly acquiesced to Federal pressure and adopted regulation of cannabis statewide. The time has come, nearly a century later, to reintroduce cannabis oil for medicinal use in Kansas. The hemp Extract Bill was recently signed into law by Governor Nixon, placing Missouri in the company of 23 states that have passed similar legislation to bring cannabis oil to children with intractable epilepsy.

In Missouri, the law allows two specific groups to receive cannabis oil treatment: (i) residents 18 or older with intractable epilepsy, or (ii) children under the age of 18 with intractable epilepsy, under the supervision of a parent or legal guardian. Intractable epilepsy means that the child has tried at least three medications and/or treatments and is still having reoccurring, unprovoked seizures.

Congratulations to the state of Missouri for this small but necessary step. We hope that Kansas does the same. Please understand that the Epilepsy Foundation of Missouri and Kansas is not in favor of recreational use of marijuana.

Missouri's bill does not mean:

It does not mean that you can smoke pot and believe you are exempt from arrest because you have epilepsy. Only individuals with hemp extract registration cards may purchase hemp extract from a CBD Oil Care Center. You cannot go to a Care Center, state you have epilepsy and expect to receive cannabis oil.

Nor does the law give you permission to purchase oil or marijuana over the internet. You may only purchase the cannabis oil from a CBD Oil Care Center if you have the correct documentation. Importantly, you cannot travel outside the state of Missouri with the oil. There will be six CBD Oil Care Centers in Missouri, subject to state approval.

There will be two licenses issued to growers. Licenses have not been issued to growers, as yet. Once the plant is grown and the oil extracted, it will be sent to the Care Centers and be available for purchase.

Hemp Extract for people with intractable epilepsy is here to stay in Missouri and I hope Kansas, too. The Epilepsy Foundation fully supports this bill.

Darla Templeton, CEO

Epilepsy Foundation Missouri and Kansas

February 11, 2015

Committee on Health and Human Services
State Capitol
300 SW Jackson
Topeka, KS 67401

Reference: HB2282

Honorable members of the Subcommittee on Health and Human Services:

As Kansans and grandparents of a child who has a medically refractory seizure disorder, we speak on behalf of our entire family in asking that you give the passing of HB2282 your heartfelt consideration. It has been a very difficult journey for all of us, especially when our daughter, son-in-law and grandson cannot legally cross the state line from Colorado back into Kansas to visit knowing that the cannabis oil that our grandson is taking as a medical treatment is not legal in our state. Not being readily close to our grandson has been extremely taxing on our whole family.

Since the age of 2 months our grandson Otis Reed has had a rare form of epilepsy for which no FDA-approved anti-seizure medications or other standard medical treatments have been effective in controlling the hundreds of seizures he suffers each day. After seeking treatments and advice from pediatric neurology teams at Children's Mercy Hospital in Kansas City, St. Louis Children's Hospital and Cleveland Clinic, the conclusion was made that the last resort was a hemispherectomy. Disconnecting or removing half of our grandson's brain would, at best, be only 50% effective as his seizure activity is scattered throughout his brain and not originating from ~~in~~ one location.

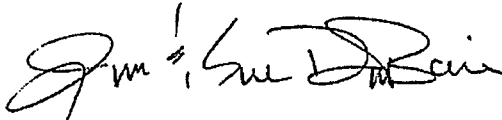
With no other medical options remaining, our daughter, son-in-law and grandson moved to Colorado to start Otis on treatments with cannabis oil commonly known as "Charlotte's Web" which is high in Cannabidiol (CBD) and low in Tetrahydrocannabinol (THC). Due to the high dosage of the benzodiazepine (which has been determined to be more addictive than heroin) that Otis has been prescribed by his neurologist to help control seizures and the severe side effects he had suffered from taking this and other FDA-approved drugs, it will be a slow process of weaning him off of his current medication and supplementing it with the cannabis oil. We have noticed over the past several months since our grandson has been on the small dosage of Charlotte's Web that there have been significant improvements in his cognitive skills with him sleeping better, laughing, and smiling every day, and becoming more focused.

We only want what is best for our grandson and countless other Kansas children that can benefit from the use of cannabis oil, who are suffering from similarly debilitating forms of epilepsy. We would like to

think that Kansas would be on the forefront of helping children and not forcing families to go elsewhere to seek medical help.

Thank you for your consideration!

Respectfully,

A handwritten signature in black ink, appearing to read "Jim & Sue DuBois". The signature is written in a cursive style with a large initial "J" and "S".

Jim and Sue DuBois



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"We change laws."

February 16, 2015

Chairman Daniel Hawkins
House Standing Committee on Health and
Human Services
Kansas State Capitol
300 SW 10th St.
Topeka, Kansas 66612

Regarding: HB 2282
Position: Support

Dear Chairman Hawkins:

On behalf of the Marijuana Policy Project (MPP) – a non-profit organization that advocates for sensible and compassionate policies related to cannabis and medical hemp – I am writing to support HB 2282. We thank Rep. John Wilson for sponsoring this important legislation, which would provide relief to victims of dangerous seizure conditions.

Purpose

House Bill (HB) 2282 would establish a regulatory framework for a system to provide seizure patients access to products containing cannabidiol, or CBD — one of several active ingredients contained in the plant *Cannabis sativa* L. Unlike comprehensive medical marijuana programs, this system would be limited to forms of the plant that are low in THC (the psychoactive ingredient), but high in CBD. While CBD has no psychoactive effect, thousands of patients across the U.S. have found it helps reduce the severity and frequency of seizures.

There are important differences between this approach and those used in states with broad medical marijuana programs. Aside from the fact that the products are limited to high-CBD, low THC amounts (capped at 3%), this bill would establish a relatively small state program. Business activity would be modest. Where often there are several different types of businesses which need to be licensed and supervised, this bill establishes just two types of business: those entities that cultivate, process, and provide CBD products, and independent testing labs to ensure products are safe. Patients may not grow their own medical hemp plants under this system.

Further, the products made available here contain little value on the illicit market. While security is an important component of the proposed regulations, diversion into the underground market is not the concern it might be in those states with broader programs.

Currently, 11 states have established laws that also try to implement regulated access to CBD products, including Alabama, Florida, Iowa, Kentucky, Mississippi, Missouri, North Carolina, South Carolina, Tennessee, Utah, and Wisconsin. Unfortunately, nearly every one of them has created a system that is unworkable. This bill borrows heavily from the one system we do believe is functional — Missouri's — and implements important additional features that are a part of many successful and well-regulated programs in states with comprehensive laws. We believe this bill represents the state-of-the-art when it comes to CBD regulation.

Seizure Conditions in the United States

This bill is designed to help victims of seizure conditions. Seizures are caused by abnormal electrical activity in the nervous system, sometimes described as an electrical storm in the brain.¹ As a result, a person's body shakes rapidly and uncontrollably as his or her muscles contract and relax repeatedly. Common symptoms include blackout periods, twitching and jerking limbs, drooling or frothing at the mouth, eye movements, grunting and snorting, loss of bladder or bowel control, sudden and uncontrolled falling, and teeth clenching.²

There are many different kinds of seizures, and causes vary widely. They can include abnormal levels of sodium or glucose in the blood, brain infection, brain injury or tumors, heart disease, Phenylketonuria (PKU), which can cause seizures in infants, and many other causes. Sometimes no cause can be identified. These are called idiopathic seizures, usually seen in children and young adults, but they can occur at any age. If seizures repeatedly continue after the underlying problem is treated, the condition is called epilepsy.³

Over two million people in the U.S. have some form of epilepsy, and there are about 150,000 new cases of seizure disorders including epilepsy diagnosed each year. One in 26 people in the United States will develop epilepsy at some point in their lifetime.⁴ About one-third of people with epilepsy live with uncontrollable seizures because standard available forms of treatment do not work for them,⁵ and it is for this group that products containing CBD show a great deal of promise.

Epilepsy affects more than 300,000 children under the age of 15 — and more than 90,000 young people have seizures that cannot be adequately treated, and children and adolescents are more likely to have epilepsy of unknown or genetic origin.⁶ Seizures are extremely dangerous, can be life-threatening, and affect every part of a person's life.⁷ For parents of children with seizure conditions, the stress can be overwhelming.⁸

Thousands of patients across the country successfully use products containing CBD to help alleviate the severity and the frequency of seizures. Unfortunately this treatment is not currently available in Kansas and some residents have had to relocate to other states for treatment. HB 2282 provides a solution.

Many with seizure conditions find relief though CBD products

As mentioned, about one in three patients with seizure conditions find that existing medical options do not help. CBD's positive effects on individuals with seizure conditions have recently become headline news as more seriously ill patients and parents of children with seizure conditions seek

¹ University Of California, Berkeley, "Researchers Create Model Of Brain's Electrical Storm During A Seizure," *Science Daily*, March 1, 2005. <http://www.sciencedaily.com/releases/2005/02/050224122911.htm>

² U.S. National Library of Medicine, National Institutes of Health National Institutes of Health, MedlinePlus, <http://www.nlm.nih.gov/medlineplus/ency/article/003200.htm>

³ *Id.*

⁴ Patricia O. Shafer, RN, MN, "Epilepsy, the Basics," Epilepsy Foundation, <http://www.epilepsy.com/learn/about-epilepsy-basics>.

⁵ *Id.*

⁶ American Association of Neurological Surgeons, "Epilepsy," <http://www.aans.org/Patient%20Information/Conditions%20and%20Treatments/Epilepsy.aspx>

⁷ Reviewed by Joseph I. Sirven, MD and Patricia O. Shafer, RN, MN, "Impact," Epilepsy Foundation, <http://www.epilepsy.com/learn/impact>

⁸ WebMD, "Caring for a Child with Epilepsy," <http://www.webmd.com/epilepsy/guide/caring-child-epilepsy>

relief through the use of CBD.⁹ A recent television special by well known physician Dr. Sanjay Gupta has brought particular attention to it's therapeutic effect on children with this condition.¹⁰

In April, 2014, the Epilepsy Foundation formally advocated for ensuring seriously ill patients have access to medical hemp.¹¹ Epilepsy Foundation's President and CEO Philip M. Gattone and Warren Lammert, Chairman of the Epilepsy Foundation Board of Directions announced:

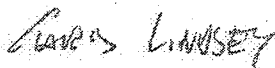
The Epilepsy Foundation supports the rights of patients and families living with seizures and epilepsy to access physician directed care, including medical marijuana.¹² Nothing should stand in the way of patients gaining access to potentially life-saving treatment. If a patient and their healthcare professionals feel that the potential benefits of medical marijuana for uncontrolled epilepsy outweigh the risks, then families need to have that legal option now -- not in five years or ten years. For people living with severe uncontrolled epilepsy, time is not on their side. This is a very important, difficult, and personal decision that should be made by a patient and family working with their healthcare team.
[Footnote supplied.]

Quite simply, the legislature should not stand between a doctor and a patient or in the case of minors, that patient's family.

Conclusion

Seizure conditions are serious and can have a devastating impact on a person's life. They affect millions across the nation and a significant number of adults and children in Kansas. These patients deserve access to any form of treatment that can help them, and CBD has transformed lives and shown genuine promise for countless individuals and families in the states that allow access. We hope Kansas will follow the recommendation of the Epilepsy Foundation and the lead of the other state programs by allowing physicians to make recommendations they believe are in the best interests of their patients. Please vote to pass HB 2282 to the floor of the House for a vote.

Sincerely,



Chris Lindsey
Legislative Analyst
clindsey@mpp.org
(202) 905-2036

⁹ Lisa Bernard-Kuhn, The Cincinnati Enquirer, "Families move to secure medical marijuana for kids," USA Today, March 23, 2014, <http://www.usatoday.com/story/news/nation/2014/03/23/families-move-to-secure-medical-marijuana-for-kids-6755071/>

¹⁰ Dr. Sanjay Gupta, "Weed," CNN, August 11, 2013, http://www.youtube.com/watch?v=Z3IMfIQ_K6U

¹¹ Philip M. Gattone and Warren Lammert, "Epilepsy Foundation Calls for Increased Medical Marijuana Access and Research," February 14, 2014.

¹² "Hemp" is used to describe Cannabis sativa L plants that contain low amounts of THC. "Marijuana" can refer to any time of cannabis plant but typically refers to varieties containing higher amounts of THC than allowed under HB 2282.