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February 12, 2014

To the Legislature:

I am a Colorado physician who has helped to treat scores of children who have severe seizure disorders with cannabidiol extract (CBD oil).

These children suffer daily from damaging epileptic seizures that are not stopped by any approved seizure medication. They also suffer from the known side effects and organ damage of the approved medications, many of which are psychoactive and can cause either severe lethargy or aggressive behavior and rage.

A series of studies and clinical observations over centuries have shown the potential of cannabis in treating epilepsy.

In 1988, the Honorable Francis Young, a federal judge, found that there is no lack of accepted safety for use of cannabis under medical supervision. Quoting Judge Young: "The evidence in this record clearly shows that marijuana has been accepted as capable of relieving the distress of great numbers of very ill people, and doing so with safety under medical supervision."
(Reference: www.druglibrary.org/schaffer/library/studies/YOUNG/young.html)

Cannabidiol has been reported by the National Institutes of Health to be a neuroprotective antioxidant, and the United States federal government patented CBD for use as a neuroprotectant and antioxidant in 2003. This means that CBD can potentially protect and heal the brains of children and adults who have epilepsy.

When children respond well to cannabidiol, their seizures are significantly reduced, and they are able to reduce or stop other medications. This relieves much of the ongoing damage to their nervous system and other organs. They can start to develop and learn in ways that haven't been possible for years. The children also appear to be helped by the neuroprotective and antioxidant effects of cannabidiol.

It is possible that cannabidiol has long term side effects that we don't know about. Given that humans around the globe have used cannabis for many centuries, any long term adverse effects must be minor, or they already would have been reported in some way.

In contrast, many of the medications currently given to children have severe, known damaging effects that the children suffer from every day.

Randomized controlled human trials are needed to clarify the use of cannabis to treat seizures. Doctors and researchers have called for these studies for decades. However, advanced studies are still prohibited by restrictive laws and by stigma.

Given that cannabis is known through medical experience and scientific study to be far safer and often more effective than medications currently in use, the need for more human studies cannot be used as a valid reason to prohibit access to cannabidiol extract (CBD oil).

Respectfully,

Margaret Gedde, MD, PhD

Good Morning!

Thank you for letting me take the time to share our journey about our son. My name is Sherri Kroening and I have an adorable son Jake who was born on April 26, 1996 who will be 18 this year.

Since Jake was nine months old he has suffered from Epilepsy called Lennox Gastout Syndrome. This type of Epilepsy is a severe form of Epilepsy ranging from Tonic CLonic, Atonic, Myoclonic, and Absence seizures. It causes cognitive impairment, developmental delay that is progressive and huge behavioral problems. LGS considerably takes time and effort by both parents 24 hours a day and 7 days a week. Doctors could never tell us why Jake has developed Epilepsy. Our doctor has told us that Jake is at increase risk of sudden death in Epilepsy due to his uncontrollable seizures and his age.

For 18 years we have watched our son have over 20-30 seizures a day along with weekly Tonic Clonic seizures. Try to imagine what it is like to watch someone you love become so aggressive before a seizure is about to happen that they self abuse themselves from pulling their hair, head banging their head on the floor, bite themselves and bite you, start to throw things at you and come at you full force wanting to hit you until the seizure activity stops in their brain. Try to then imagine the person you love convulsing their whole body in front of you why you time the seizure, and keep them safe, and then pray to God that the seizure ends soon. When the seizure does end this person you love is lying helpless and can't even move their body. For our Jake he then urinates after a Tonic Clonic seizure and we have to try and lift this 18 year old man who can't move his body at all and clean him up and drag him into a safe bed because he can't walk after a seizure. We have never heard our Childs voice, never saw him interact with toys, and is still not trained to use the bathroom due to all the constant seizures in his daily life.

We have tried over 15 FDA approved seizure medications with no success in seizure control for our son. Jake has horrible side effects from the medicine he is currently on and has taken in the past. Side effects like dizziness, headaches, stomachaches, nauseated, anxiety, depression, weakness, **increased seizures from some of the medication along with huge constipation issues and behavioral problems with many** of them. Imagine giving a 18 year old a weekly Enema due to severe constipation from seizure medications. Jake has had the Vagus Nerve Simulator implanted with no success; due to Jake's epilepsy in his brain surgery is not an option for him. So we tried the ketogenic diet a very high fat diet that brings your body into ketosis that helps some individuals with Epilepsy. We tried this diet when Jake was 5, when he was 10, and just recently again when he was 16. We keep trying the diet because there is nothing left to try and the medicines have never helped and only caused him more problems.

As Jake is turning 18 it's a whole new chapter for us. Only three more years left of school and then where do I turn for help??? We already started looking at adult day programs and I'm limited on where I can send him because of his severe medical needs and aggression from seizures. We are physically and emotionally exhausted of the constant care that is needed for our sons Epilepsy. If we his parents can't handle this much longer because of what it is doing to our own health, what does that mean for the state of WI??? It means the state and fed government will be supporting Jake for 24 hour care which is costly due to my research. It's going to cost over \$110,000.00 a year just for care and not to mention all of his other needs for living.

Epilepsy has consumed our daily life with heartbreak, helplessness, stress, frustration, tears & anger. For 18 years we have been up every night with seizures and our son is wide awake at 3:00 am every day due to seizure activity. I can't remember the last time we were able to sleep five hours without any

uninterrupted sleep. I challenge anyone here today to come live our life for 24 hours and tell me at the end of the day after watching seizures after seizures, aggression from the seizures, cleaning up urine accidents daily, attending to his every want and need constantly, and being worried that it might be his last day on earth due to the risk of sudden death in epilepsy that you wouldn't want a better quality of life for your child.

The results in CO are so inspiring to us on how CBD oil has helped over 300 beautiful children suffering from Epilepsy. I ask every one of you to please give us a chance to help our son with CBD oil to calm his brain and help with his seizures. Give us a chance to hopefully have our son show some cognitive improvement without 20 to 30 seizures a day so we are able to take care of him in his future and that he can be a part of this community. I sincerely thank you for your time today.

Sincerely,

Sherri Kroening
N95 W25867 Riverview Drive
Colgate, WI 53017

Sappenfield, Anne

From: Thorson, Randy
Sent: Wednesday, February 19, 2014 11:54 AM
To: Allen-Hubka, Theresa; Bates, Katherine; Polzin, Cindy M - GOV; Clark, Lauren; Deej Lundgren; Divine, Kathy; Emerson, James; Hanus, Andrew; Karius, Bob; McKinny, Chris; Morouney, Lonna; Ohly, Mitchel; Posca, Dan; Rep.Billings; Rep.Endsley; Rep.Johnson; Rep.Kahl; Rep.Kerkman; Rep.Krug; Rep.Loudenbeck; Rep.Neylon; Rep.Schraa; Rep.Spiros; Rep.Taylor; Rongstad, Tami; Sabrina Gentile; Sappenfield, Anne; Schultz, Rusty; Thorson, Randy; Tierney, Michael; Trost, Craig; Ullsvik, Christian; VerVelde, Brandon; Walsh, Patrick; Zikmund, Alison
Subject: FW: My niece Lydia was born with kleefstra's syndrome

Final piece of submitted testimony for AB 726 (CBD).

Thank you for your attention.

Have a great day/week/month/Spring (upcoming)

Randy

-----Original Message-----

From: Brian Blume [<mailto:brianblume@me.com>]
Sent: Wednesday, February 12, 2014 1:55 PM
To: Sally Schaeffer; Rep.Krug; Thorson, Randy
Subject: My niece Lydia was born with kleefstra's syndrome

Testimony for Brian Blume:

My niece Lydia was born with kleefstra's syndrome and has endured so much in her short life. She has many battles ahead of her as well.

Lydia has a big health problem right now...seizures. Fortunately, there is a medicine called CBD that will likely help her. Unfortunately, my niece Lydia doesn't have access to this medicine because she is a resident of Wisconsin.

Her seizures are severe enough that brain surgery has been discussed as a "possible" way to end her seizures. I ask who in the room would opt for brain surgery for their child BEFORE exploring EVERY single option available to them?

Currently, CBD is an option that makes sense but it is not legal in Wisconsin. According to the current law in Wisconsin...Lydia should have brain surgery, and have a portion of her brain removed, instead of first having access to a proven (and more importantly) non invasive medicine (CBD) that she needs.

Making progress is hard for my niece. Lydia, along with my sister Sally and my brother in law Tom, fight for every little milestone. Milestones like eating by themselves and walking are givens for most parents...for Lydia these are major victories. The seizures set back Lydia's development and those hard fought milestones start to disappear. That is why time is of the essence in moving this bill forward into law.

I ask that CBD be made available for prescription for Lydia and all others with seizure disorders. I also ask that you not get bogged down in the minutia and move this bill through in fastest way possible because your urgency with bill 726 can save Lydia's life as well as many others.

This is common sense legislation and an opportunity for legislators to provide real and needed help to Wisconsin families dealing with seizures.

Thank you.

Brian Blume
262.378.0142

Sent on the run....