



# Van H. Wanggaard

Wisconsin State Senator

## Testimony on Senate Bill 222

About a year and a half ago, the Wisconsin Legislature passed “Lydia’s Law.” Lydia’s Law allowed for a doctor or pharmacist to dispense Cannabidiol, or CBD Oil, and set up a mechanism for the state to help with the availability of CBD Oil in Wisconsin. Lydia’s mother is here and will testify about the bill shortly.

Unfortunately, in the last year, we have discovered that despite its best intentions, the 2013 Legislature has had little impact on the availability of CBD Oil in Wisconsin. Because of the regulatory hurdles involved with CBD Oil, the lack of a current clinical trial in Wisconsin for CBD, and, frankly, a lot of the misinformation about CBD Oil, those that need this potential life-changing medicine are still unable to obtain it. In fact, at least one family we are aware of has moved to Colorado to be able to access this medicine.

Senate Bill 221 is narrowly drafted to help address just one of the hurdles that a family seeking CBD oil will face. The bill specifies that CBD Oil without a psychoactive effect is not a Schedule One Drug – with or without a prescription. The remainder of Lydia’s Law remains in place.

The intent of the bill is simple – if a person possesses CBD Oil without a psychoactive effect, they need not fear prosecution from local authorities. And I do not want this bill to go further.

There is a lot of misinformation about this bill and about CBD in general, so it important for me to specify what this bill does NOT do.

- This bill does not legalize marijuana
- This bill does not legalize medical marijuana
- This bill does not allow for the growing of marijuana in Wisconsin
- This bill does not allow for the cultivation of marijuana in Wisconsin
- This bill does not allow for the manufacture of CBD oil in Wisconsin
- This bill does not allow for the sale or transfer of CBD oil in Wisconsin.
- This bill will not lead to street corner drug sales of CBD oil.

Here’s the only thing the bill will do: Allow a person to possess CBD Oil without psychoactive effect in Wisconsin. There are still federal hurdles to overcome, and we are working with our federal legislators, including Speaker Ryan, and both US Senators to decriminalize CBD Oil without a psychoactive effect – HR 1685. Regardless of what happens at the federal level, we should not prosecute them for possessing a drug that does not give them a high and reduces or eliminates seizures in their child.

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My comments are short, because the bill is simple. But more importantly, I'm going to be brief because you need to hear from people far more important than me on this issue – the families

You will hear from a lot of families today about the harmful effects that these persistent seizures have on their families. But more importantly, I want you to listen closely and carefully when they speak of CBD oil.

You will hear the passion in their voices when they speak about their children and this treatment. You will hear the positive effects that CBD oil has had on children with seizures. How parents can sleep again, less worried about their child making it through the night. You will hear them full of hope, for their children, for their families, for the future. And they hope the Legislature will hear them, and fix this law so that they can finally possess this life saving medicine without fear of arrest.

Thank you for your attention and I'll be happy to answer any questions.



Thank you again for this opportunity to provide the Society's testimony on Senate Bill 221. Please feel free to contact the Society on this and other health-related issues; we look forward to continued collaboration with the state's policymakers on enhancing Wisconsin's health care system.

### **Further Information**

#### AMA policy: **H-95.952 Cannabis for Medicinal Use**

- (1) Our AMA calls for further adequate and well-controlled studies of marijuana and related cannabinoids in patients who have serious conditions for which preclinical, anecdotal, or controlled evidence suggests possible efficacy and the application of such results to the understanding and treatment of disease.
- (2) Our AMA urges that marijuana's status as a federal schedule I controlled substance be reviewed with the goal of facilitating the conduct of clinical research and development of cannabinoid-based medicines, and alternate delivery methods. This should not be viewed as an endorsement of state-based medical cannabis programs, the legalization of marijuana, or that scientific evidence on the therapeutic use of cannabis meets the current standards for a prescription drug product.
- (3) Our AMA urges the National Institutes of Health (NIH), the Drug Enforcement Administration (DEA), and the Food and Drug Administration (FDA) to develop a special schedule and implement administrative procedures to facilitate grant applications and the conduct of well-designed clinical research involving cannabis and its potential medical utility. This effort should include: a) disseminating specific information for researchers on the development of safeguards for cannabis clinical research protocols and the development of a model informed consent form for institutional review board evaluation; b) sufficient funding to support such clinical research and access for qualified investigators to adequate supplies of cannabis for clinical research purposes; c) confirming that cannabis of various and consistent strengths and/or placebo will be supplied by the National Institute on Drug Abuse to investigators registered with the DEA who are conducting bona fide clinical research studies that receive FDA approval, regardless of whether or not the NIH is the primary source of grant support.
- (4) Our AMA believes that effective patient care requires the free and unfettered exchange of information on treatment alternatives and that discussion of these alternatives between physicians and patients should not subject either party to criminal sanctions. (CSA Rep. 10, I-97; Modified: CSA Rep. 6, A-01; Modified: CSAPH Rep. 3, I-09; Modified in lieu of Res. 902, I-10; Reaffirmed in lieu of Res. 523, A-11; Reaffirmed in lieu of Res. 202, I-12; Reaffirmed: CSAPH Rep. 2, I-13)

*The New Republic* – “The Wonder Drug: Inside the medical marijuana industry's wild new frontier”  
<https://newrepublic.com/article/122918/wonder-drug>

South Carolina: CBD oil from hemp; legislation

<http://www.wtoc.com/story/29097564/sc-mom-legally-making-and-selling-strain-of-medical-marijuana>

[http://www.scstatehouse.gov/sess120\\_2013-2014/bills/839.htm](http://www.scstatehouse.gov/sess120_2013-2014/bills/839.htm)

Texas: Passes CBD bill – requires physician approval; legislation

[http://www.huffingtonpost.com/2015/06/01/texas-legalizes-marijuana\\_n\\_7486232.html](http://www.huffingtonpost.com/2015/06/01/texas-legalizes-marijuana_n_7486232.html)

<https://legiscan.com/TX/bill/SB339/2015>

Marijuana-derived edibles: retail promotion

[http://www.huffingtonpost.com/the-new-england-journal-of-medicine/marijuana-edibles\\_b\\_7347814.html](http://www.huffingtonpost.com/the-new-england-journal-of-medicine/marijuana-edibles_b_7347814.html)

Marijuana Extract for Children Questioned

<http://www.wsj.com/articles/marijuana-extract-for-children-with-epilepsy-is-questioned-1427148386>



## Warning Letters and Test Results

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In late February 2015, FDA issued several warning letters to firms that market unapproved drugs for the diagnosis, cure, mitigation, treatment, or prevention of diseases. Some of these firms claim that their products contain cannabidiol (CBD). FDA has tested those products and, in some of them, did not detect any CBD. It is important to note that these products are not approved by FDA for the diagnosis, cure, mitigation, treatment, or prevention of any disease, and often they do not even contain the ingredients found on the label. Consumers should beware purchasing and using any such products.

The links to the Warning Letters and the test results for the CBD-related products are below:

Firm	Product	State	Purchase Website	Lab Results %(w/w)		
				CBD	$\Delta$ 9-THC	Other Cannabinoids
Canna Companion, LLC	Canna Companion Capsule Size: 4	WA	cannaforpets.com	0.1%	0.1%	CBDA: 0.3% THCA: 0.9%
Canna-Pet, LLC	CBD Wedges - Canna-Biscuits for Dogs	WA	canna-pet.com	None detected above 0.1% (w/w)		
Canna-Pet, LLC	Canna-Pet for Cats	WA	canna-pet.com	0.5%	—	—
Canna-Pet, LLC	Canna-Pet MaxCBD Capsules for Dogs	WA	canna-pet.com	2.6%	0.1%	CBC: 0.1%
CBD Life Holdings LLC dba Ultra CBD	UltraCBD*	AZ	ultracbd.com	None detected above 0.1% (w/w)		

## Warning Letters and Test Results

CBD Life Holdings LLC dba Ultra CBD	UltraCBD*	AZ	ultracbd.com	0.02%	ID only	CBDA: 0.02%
Hemp Oil Care	Hemp Pure Vape E-Drops: Peached	CA	hempoilcare.com	negative for cannabinoids		
Hemp Oil Care	Cibaderm Hemp Salve	CA	hempoilcare.com	—	—	CBDA: 0.2%
Hemp Oil Care	Cibdex Hemp CBD Complex Drops - Peppermint	CA	hempoilcare.com	0.3%	—	—
Hemp Oil Care	Cibdex Hemp CBD Complex Drops - Unflavored	CA	hempoilcare.com	0.3%	—	—
Hemp Oil Care	Cibdex Hemp CBD Complex Drops - Vanilla	CA	hempoilcare.com	0.3%	—	—
Hemp Oil Care	Hemp Honey 21% Cannabidiol Oil	CA	hempoilcare.com	negative for cannabinoids		
Hemp Oil Care	Hemp Honey CBD Vape Oil - Blueberries & Cream	CA	hempoilcare.com	negative for cannabinoids		
Natural Organic Solutions	CBD Oil Extract Capsules (500mg - 10 Capsules)	WA	purecbd.net	negative for cannabinoids		
Natural Organic Solutions	Real CBD Extract - CBD (Cannabidiol) Cannabis Extract Capsules (1500mg - 30 Capsules)	WA	purecbd.net	0.5%	0.20%	CBDA: 0.1% THCA: 0.03% CBN: ID only
Natural Organic Solutions	21% CBD Hemp Oil Treatment	WA	purecbd.net	negative for cannabinoids		
Natural Organic Solutions	26% CBD Hemp Oil Treatment	WA	purecbd.net	0.14%	0.45%	CBDA: 0.05% CBN: ID only
Twin Falls Bio Tech, LLC	Arisi-Tol	SC	arisitol.com	0.2%	—	—

\*Multiple samples tested

**Abbreviations:**  $\Delta$ 9-tetrahydrocannabinol ( $\Delta$ 9-THC), Tetrahydrocannabinol (THC), Cannabidiol (CBD), Cannabinol (CBN), Cannabidiolic Acid (CBDA), Tetrahydrocannabinolic acid (THCA), Cannabichromene (CBC)

### More in Public Health Focus

Expanded Access (Compassionate Use)

Page Last Updated: 08/05/2015

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## U.S. Food and Drug Administration

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Silver Spring, MD 20993

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To those on the committee, I thank you for your time today. Your consideration and your full attention today to hear from those sharing their thoughts to help change Lydia's Law to make CBD oil accessible to those that want and need it.

My name is Sally Schaeffer. You may know me from the first time many strong parents were here almost 2 years ago. Or you may know me from the news where I introduced Lydia to the State of Wisconsin, sharing about her rare epilepsy disorder. Or maybe you saw when she died on Mother's Day 2014 and again I shared with the country about this tremendous loss to our family.

There is something to be said for being a momma bear. A mother who will go to the ends of the earth to try to save her child. The voice for their child who cannot speak. An advocate to make sure they are getting the best education and care. The eyes who read the prescription pill bottles to understand all of the side effects. The mother who continually puts the puzzle pieces together to help physicians decipher what is wrong.

I thought I was that momma bear in April 2014 – coming here with a coalition of other parents – all fighting for what we felt should be a right – the access to CBD oil. After many months of beating myself up over this failed law I realized we didn't fail our children, I didn't fail Lydia. This law failed our loved ones. A law with a provision that makes it impossible to access it. We were failed.

But we can't dwell on that now...fixing the mistake that has been made is what we need to do. And I'm thankful that Senator Wanggaard has stepped up to help amend this. To help those that want and need access. No matter what I'm here and until we get a law that works, I will be back again and again. Because my daughter's life means something not only to me but others that want access. It means showing you what can happen if we don't fix this. It means burying more people.

Going back...A little bit about Lydia – she was born with a rare genetic chromosome disorder called Kleefstra syndrome. She at the age of 7 was diapered, needed to be fed, bathed, dressed, was non-verbal and learned to walk undirected at the age of 5. Her mental capabilities were that of a 1 year old. She was also diagnosed with epilepsy.

Along with this syndrome came health anomalies, one of which included epilepsy. In June 2013 she was diagnosed with a rare epilepsy called Electrical Status of Slow Wave Sleep, otherwise known as ESES. My husband always said "I hate laying her to sleep – I hate putting her down at night because we have no idea if she is seizing." He was right- with this disorder when we laid her down in bed and she appeared to be sleeping soundly her brain was actually seizing over 80% of non-REM sleep. 80%. She wasn't in fact sleeping at all.

Epilepsy can lead to SUDEP – this is sudden unexpected death from epilepsy. It is what we believe occurred to Lydia. She had a beautiful day before she died – she ate well, she played in the beautiful sunshine. People who drove past our house later commented on how happy she looked and how her life made them think twice about their blessings.

At the last hearing I testified at I spoke about how I held my breath every time I opened Lydia's door in the morning. I was so afraid our worst nightmare would come true. My husband, was the one that morning. He was the one who opened the door saying "come on sweet pea, it is time to get up...come

on” only to see her blue foot sticking out from under the blanket. He panicked and rushed to her bed thinking it was a horrific seizure only to find her face down between the pillow and the bed.

As he grabbed her arm he felt her rigidity that had started to occur. Her face was purple and blue and blood was coming out of her nose and mouth. He screamed. He blacked out. He yelled for help. 911 was called. And then because I was out of town he called me sobbing like I’ve never heard before telling me there was nothing they could do. I hunched down in front of a big picture window hardly believing what I was hearing. I collapsed into my own mother’s arms.

When I arrived home I wanted to crawl in bed with my little girl...I wanted to touch her one last time. I couldn’t believe after 7 years of fighting for everything she needed she was gone. Just like that. In her sleep. My husband stopped me from touching her. Through his tears he suggested I remember her soft, pliable skin – not like the feeling he had. The one that would haunt him for days, months and even now.

Death affects everyone in our family. My 11 year old won’t hardly mention her in fear of us hurting more. My 5 year old asks to be buried in the backyard so he can go to heaven to get her. He wonders why God won’t give her back and tries to understand death. When you leave my house he will have to wave goodbye and when asked why he will say “because I never got to say goodbye to Lydia.” He suffers from separation anxiety telling me “I’m afraid I’ll never see you again.” I could go on – you get the point, you understand. This isn’t just 2 parents missing Lydia, it is my family, my mother, my best friend and all the people in this room and around the country that have stood beside me since May 11, 2014.

So when we were all fighting for this law we all knew SUDEP could happen. We all had heard about it and it was our biggest fear. But sadly, for me – it became our reality. Our reality that all we have left now are memories, pictures, videos and the worst part – a head stone.

So, when you look around and you wonder where all your parents are that were here last time. A lot of them are at home. They are disappointed. They are tired. They are caregiving. Most of all – they are scared. So scared to be walking in our shoes. To plan a wake, a funeral and most importantly – have NOTHING left but this pain.

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Last week, I had the pleasure and honor of being in Washington DC regarding the Federal bills – HR 1635 and S1333 for access to therapeutic CBD hemp oil. Both bills allowing access without stipulations on ailments. This was my second trip to Washington.

With a coalition of mothers and grandmothers from across the country we visited House and Senate members from across the country. One mother, Lisa Smith came with her daughter Haley, she was featured on Dateline NBC this summer – Growing Hope (give DVD). Virginia recently passed their bill similar to what we are doing here in Wisconsin – that if you have it – you will not be prosecuted.

On my first trip in March Haley didn’t have access to the oil yet and was in a comatose state. She was up only once during a full day of meetings, otherwise sleeping most of the day due the side effects of her pharmaceutical meds and her massive seizures from Dravet Syndrome.

Last week with Haley now being on the oil for some time now she did things she had never done before. She danced in the hallways, was interactive, vocal, playing and even pushing her wheelchair. I have videos of her doing the hula in the hallway. Her seizures are reduced by 40%.

I'd like to show you a bit from Dateline

- 18:25 – 20:22
- 49:48 – 50:20

Let me talk more about our federal efforts... An amendment was recently adopted to an appropriations bill by a vote of 297-130 that states the Justice Department (which the DEA is a part of) cannot spend money on any action (Prosecuting) that would prevent a state from allowing CBD, distributing it or using it. 297-130. Due to the large bipartisan support of this amendment indicates there is overall support for the legislation.

Second, our co-sponsors for the federal bill.... first...In all of our meetings on the hill we didn't have anyone oppose these bills. In fact, in 8 months we have 60 co-sponsors on the House bill and 10 on the Senate companion bill. Now we certainly want to keep this moving in Wisconsin due to States Rights, however it is hard to deny the immense support from the Senate side - Senator Ron Johnson, Senator Tammy Baldwin – both of whom I met and relayed they would do anything to help us with this effort.

On the House side we have Congressman Sensenbrenner and Speaker Ryan – again both of whom I met in Washington and they too provided their support. And we have Congressman Grothman also a co-sponsor. As you may know it is unusual that Ryan co-sponsors a bill and unprecedented to be Speaker of the house and co-sponsor. In his office last week he told me he fully supports this and it will pass. You obviously can't deny the bipartisan powerhouses from Wisconsin that are in full support of the federal bill. I hope you follow suit of your US legislators here in Wisconsin.





# COMMONWEALTH of VIRGINIA

Office of the Lieutenant Governor

Ralph S. Northam  
Lieutenant Governor

(804) 786-2078  
Fax: (804) 786-7514  
TTY/TDD: 1-800-828-1120  
EMAIL: [ltgov@ltgov.virginia.gov](mailto:ltgov@ltgov.virginia.gov)

November 16, 2015

Dear Senators Alexander, Gardner, Hatch, and Wyden,

My name is Ralph Northam and I am the Lieutenant Governor of the Commonwealth of Virginia. I am also a pediatric neurologist and, in Virginia, the Lieutenant Governor is actually a part-time position, so I continue to see patients three to four days a week at Children's Hospital of the Kings Daughters in Norfolk.

As a pediatric neurologist, I see many children who suffer from neurological disorders such as epilepsy and endure intractable seizures on a regular basis. I have treated some of the children who are visiting with you and your colleagues to advocate for cannabidiol (CBD), and I urge you to listen to their stories, carefully consider the research and data, and keep an open mind.

As a policy maker, I understand the position that you are in. Fifteen states, including Virginia, have allowed access to CBD since March 2014, though the majority of these states are more conservative in their approach to public policy. You have the opportunity to exempt CBD from the legal restrictions applied to it as a Schedule 1 substance, while at the same time making sure that the Food and Drug Administration properly regulates it to make sure it's used safely and responsibly as a dietary supplement. It is important to remember that in the medical field, we routinely prescribe dozens upon dozens of medications that are derived from plants.

To put my own experience into further context, I graduated from the Virginia Military Institute and served as a doctor in the United States Army, where I treated soldiers during Desert Storm. As a State Senator, I sponsored legislation that banned smoking in restaurants. I do not approach this topic lightly and have given it serious consideration. You will find no stronger advocates for a policy than the children and parents that you will be meeting with. I have seen firsthand the positive effects CBD has had for these children, and I hope and pray that with your help they will be able to live better, healthier lives with less debilitating seizures and that their parents will be able to seek help for their sick child without fear of federal prosecution.

Please do not hesitate to reach out to me or my staff if you have any questions or would like to discuss this.

Sincerely,

A handwritten signature in black ink that reads "Ralph S. Northam".

Ralph S. Northam

60 cosponsors  
W/ Speaker Ryan  
J. Sensenbrenner  
G. Bruthman

114TH CONGRESS  
1ST SESSION

# H. R. 1635

To amend the Controlled Substances Act to exclude cannabidiol and cannabidiol-rich plants from the definition of marihuana, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

MARCH 25, 2015

Mr. PERRY (for himself, Mr. AUSTIN SCOTT of Georgia, Mr. MASSIE, Mr. HONDA, Mr. GRAYSON, Ms. NORTON, Mr. LOWENTHAL, Mr. BLUMENAUER, Mr. McCLINTOCK, Mr. JONES, Mr. BARR, Mr. DOLD, Mr. COHEN, Mr. YARMUTH, Mr. COOPER, Mr. DAVID SCOTT of Georgia, Mr. WOODALL, Mr. HANNA, and Mr. VAN HOLLEN) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on the Judiciary, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

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## A BILL

To amend the Controlled Substances Act to exclude cannabidiol and cannabidiol-rich plants from the definition of marihuana, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the "Charlotte's Web Med-  
5 ical Access Act of 2015".

1 **SEC. 2. EXCLUSION OF CANNABIDIOL AND CANNABIDIOL-**  
2 **RICH PLANTS FROM DEFINITION OF MARI-**  
3 **HUANA.**

4 (a) IN GENERAL.—Section 102 of the Controlled  
5 Substances Act (21 U.S.C. 802) is amended in paragraph  
6 (16)—

7 (1) by striking “(16) The” and inserting  
8 “(16)(A) The”; and

9 (2) by adding at the end the following:

10 “(B) Cannabidiol and cannabidiol-rich plants—

11 “(i) are excluded from the definition of  
12 marihuana under subparagraph (A); and

13 “(ii) shall not be treated as controlled sub-  
14 stances under this Act.”.

15 (b) DEFINITIONS.—Section 102 of the Controlled  
16 Substances Act (21 U.S.C. 802), as amended, is further  
17 amended by adding at the end the following:

18 “(57) The term ‘cannabidiol-rich plant’ means  
19 the plant *Cannabis sativa* L. and any part of such  
20 plant, whether growing or not, with a delta-9  
21 tetrahydrocannabinol concentration of not more than  
22 0.3 percent on a dry weight basis.

23 “(58) The term ‘cannabidiol’ means the sub-  
24 stance cannabidiol, as derived from a cannabidiol-  
25 rich plant.”.

1 **SEC. 3. OTHER LIMITATIONS.**

2 (a) **NON-APPLICABILITY OF FEDERAL FOOD, DRUG,**  
3 **AND COSMETIC ACT.**—The Federal Food, Drug, and Cos-  
4 metic Act (21 U.S.C. 301 et seq.) shall not apply to  
5 cannabidiol or cannabidiol-rich plants as those terms are  
6 defined in section 102 of the Controlled Substances Act  
7 (21 U.S.C. 802) as amended by this Act.

8 (b) **STATE LAW.**—Nothing in this Act shall prohibit  
9 or otherwise restrict any activities related to the use, pro-  
10 duction, or distribution of marijuana in a State in which  
11 such activities are legal under State law.

12 **SEC. 4. SUNSET PROVISION.**

13 The provisions of this Act, and the provisions inserted  
14 into the Controlled Substances Act by this Act, shall cease  
15 to apply on the date that is 3 years after the date of enact-  
16 ment of this Act.

○

10 cosponsors  
WD T. Baldwin  
R. Johnson  
II

114TH CONGRESS  
1ST SESSION

# S. 1333

To amend the Controlled Substances Act to exclude cannabidiol and cannabidiol-rich plants from the definition of marijuana, and for other purposes.

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## IN THE SENATE OF THE UNITED STATES

MAY 13, 2015

Mr. GARDNER (for himself, Mr. WYDEN, Mr. HATCH, Mr. ISAKSON, Mr. MERKLEY, and Mr. BENNET) introduced the following bill; which was read twice and referred to the Committee on the Judiciary

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## A BILL

To amend the Controlled Substances Act to exclude cannabidiol and cannabidiol-rich plants from the definition of marijuana, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Therapeutic Hemp  
5 Medical Access Act of 2015”.

1 **SEC. 2. EXCLUSION OF CANNABIDIOL AND CANNABIDIOL-**  
2 **RICH PLANTS FROM DEFINITION OF MARI-**  
3 **HUANA.**

4 (a) IN GENERAL.—Section 102(16) of the Controlled  
5 Substances Act (21 U.S.C. 802(16)) is amended, in the  
6 second sentence—

7 (1) by striking “or the sterilized seed” and in-  
8 serting “the sterilized seed”; and

9 (2) by inserting before the period at the end the  
10 following: “, cannabidiol, or cannabidiol-rich plants”.

11 (b) DEFINITIONS.—Section 102 of the Controlled  
12 Substances Act (21 U.S.C. 802), as amended, is further  
13 amended by adding at the end the following:

14 “(57)(A) The term ‘cannabidiol-rich plant’  
15 means the plant *Cannabis sativa* L. and any part of  
16 such plant, whether growing or not, with a  
17 tetrahydrocannabinol concentration of not more than  
18 0.3 percent on a dry weight basis.

19 “(B) A cannabidiol-rich plant shall not be treat-  
20 ed as a controlled substance under this Act.

21 “(58)(A) The term ‘cannabidiol’ means the sub-  
22 stance cannabidiol, as derived from a cannabidiol-  
23 rich plant.

24 “(B) Cannabidiol shall not be treated as a con-  
25 trolled substance under this Act.

1           “(59) The term ‘tetrahydrocannabinol concen-  
2           tration’ means—

3                   “(A) the percent of the delta-9 tetrahydro-  
4                   cannabinol content per dry weight of any part  
5                   of the plant *Cannabis sativa* L. or per volume  
6                   of weight of marihuana product; or

7                   “(B) the combined percent of the delta-9  
8                   tetrahydrocannabinol and tetrahydrocannabinol-  
9                   ic acid in any part of the plant *Cannabis sativa*  
10                  L., regardless of moisture content.”.

11 **SEC. 3. RULE OF CONSTRUCTION.**

12           Nothing in this Act, or the amendments made by this  
13 Act, shall be construed to prohibit or otherwise restrict  
14 any activities related to the use, production, or distribu-  
15 tion of marijuana in a State in which such activities are  
16 legal under State law.

○



Name- Lilith Rose Pletka-Wirth (Lily) (4)

**Diagnosis- Dravet Syndrome, SCN2a, Grin2b, Agenesis of the Corpus Callosum, Ventriculomegaly, Colpocephaly, Hydrocephalus, Dygenesis of the left frontal hemisphere, ESES, Autism, and CeliacDisease.**

Website- [www.facebook.com/lightandloveforlily](http://www.facebook.com/lightandloveforlily)

Lily is known to us and her doctors as, Our Unicorn. She is currently the only known person in the world with all 9 of her rarities combined. All 9 of her rarities cause uncontrolled Epilepsy, both in sleep and throughout her day. She is literally a mystery and miracle to the medical world. If you look up her diagnoses, you will see why.

We were told at 26 weeks gestation that our once healthy baby girl was likely not going to survive the birth because her brain wouldn't tell her body to take its first breath. We were told, if she happened to take her first breath, she wouldn't be able to walk or talk and would have no quality of life. They suggested we terminate the pregnancy. We declined their suggestion and thus started our battle to save our daughter Lily.

On February 2nd, during the huge Blizzard of 2011, when the whole city of Milwaukee, WI was shut down, our little Unicorn came flying into the world. When Lily was born she wasn't breathing, but it didn't take too long before she took her first breath and begin to show the doctors they were wrong about her and she was gonna prove them wrong everyday and fight.

Lily started to seize immediately after birth. Lily spent the next 5 days in the NICU/PICU at Children's Hospital of Wisconsin. Lily had problems with feeding right at the start and was continuing to seize. They gave her an MRI to confirm what the ultrasound and Fetal MRI already said. It was confirmed, she had 5 rare brain malformations. They concluded this was the cause of her seizures, and after consulting with a Neurologist, we were sent home to continue our battle to save Lily.

Lily was placed on Phenobarbital at a month old and had numerous EEG's and hospital stays in her first year of life. She was placed in OT, PT, and SLP therapies at birth. She was delayed globally, but still fighting. She learned to roll over, sit up, and crawl all within a month of each other, so by her first birthday she could do all those things. She started to walk at 19 months, but had a bad seizure that caused her to regress back to an infant state. She finally

regained the ability to fully walk on her own by 22 months. Her speech was very delayed. She would have little spurts where she would learn a word, but then a regression would happen and we would have to start all over again. But she kept fighting and so did we.

By the time she was 16 months old her liver was starting to fail from the Phenobarbital. We had to drive 3 hrs away because we wanted a 2nd opinion on the Ketogenic diet. Her current neuro was refusing it, stating it wouldn't help her because she wouldn't like the taste of the Keto Cal formula. So as always when told no by a doctor, we would just trust our gut and our research and fight. It was at this 2nd opinion visit, that they discovered her liver was failing and insisted we remove her from the Phenobarbital. Her own doctors missed this and it could've cost her life. We were grateful for the new doc and she agreed to the Keto diet, the problem was our insurance wouldn't pay for more than a 2nd opinion and our Neurologist in Milwaukee wouldn't support the diet even with this Neurologist's recommendation.

We were back to square one. The Neurologist in Marshfield discussed with us the risks if Lily continued on pharmaceuticals, so we decided it was best to keep her off all pharmaceuticals until her liver healed. It was a very long year.

At 2 her liver was healed, but her seizures were changing again and worsening. So back to the pharmaceutical industry we were forced. They wanted to put her on Lamictal, I refused. We tried Keppra instead, it made her turn into a demon. She was trying to hurt herself and us constantly. Her seizures were not getting any better, so we stopped it and within a few days, a switch flipped and our baby was back.

Next on the list was Trileptal. The newest EEG said she now had focal seizures due to her Dygenesis of the left frontal hemisphere (missing a part of her left frontal hemisphere). Within 24hrs on Trileptal and Lily was seizing thousands of times. It was the scariest thing we had ever witnessed. She just seized and seized over and over. We called the neuro immediately and he said to stop it immediately. We did, and the seizures slowed and eventually were back to her baseline seizures.

Back in for yet another EEG, this time the results indicated generalized Epilepsy and coming from the front, back, and both hemispheres of the brain. Every EEG was different! We asked if Dravet was a possibility and her neurologist responded that there is no way it was Dravet or LGS. He continued to try and assure us that her uncontrolled seizures were due to her brain abnormalities and he put her on Depakene.

She was also diagnosed with ESES (Electrical Status Epileptus of Sleep) at this time. This meant with this new discovery and all her brain abnormalities, she was at the highest risk for SUDEP (Sudden Unexplained Death in Epilepsy). We were sent home with a pulse/ox monitor to help us know if Lily was having big seizures in her sleep that caused her heart rate and oxygen level to drop dangerously low. It would also help us to get her help before SUDEP decided to take her from us.

Lily was also given Clonazepam and Diastat, as a rescue. Most of her status seizures were clusters, so we were instructed to use Clonazepam first for clusters and Diastat for Tonic Clonic statuses. So that's what we did. It felt like we were constantly giving her Clonazepam, and it would stop her cluster status, but then her seizures would go haywire and we would end up in the ER anyway. We were frustrated and wanted answers.

Her amazing genetic doctors believed us and told us that he believed that there was more going on here than just her brain abnormalities causing the seizures. They fought to get her a whole exome sequence genetic test. I could kiss them everyday for this, because it gave us the answers we needed to save Lily.

On October 8, 2014, we found out Lily did in fact have Dravet Syndrome. Only in Lily fashion, she had SCN2a. At that time she was 1 of 70 kids with SCN2a. SCN1a is what the majority of Dravet kids have. We also found out she has Grin2b. She was 1 of 7 kids known with Grin2b which is also known to cause intractable Epilepsy & Autism.

It almost seemed unreal, we spent over 3 years fighting with countless on call Neurologists and second opinions all leading to dead ends and being blown off because Lily didn't present like a typical child suffering from daily seizures.

The results were really a distraction, in a sense they offered a false sense of relief, as if knowing what this monster terrorizing our daughter was actually going to do, did any good in relieving Lily of her daily struggles. It seemed we were in the emergency room every other week, with Lily seizing. Each time we were seen for increased seizures the result was always the same, we were instructed to raise her Depakene. The only thing the Depakene seemed to do was knock Lily out. Which in most scenarios, I suppose maybe that was the idea. However, since Lily has ESES, which means that she seizes over 80% of the time she is asleep, it wasn't really helpful to us. This clearly wasn't working so again, we found ourselves asking the doctor about what other options she had. He suggested we add Felbamate and/or Onfi to her daily medications. We had heard nothing but horror stories about kids on these drugs. His colleague also suggested trying the Ketogenic diet. When we told him that we had suggested that before and our Neuro very strongly disagreed with us, he was shocked, but agreed then it was better to wait.

Lily's Depakene levels were usually around 160, when we originally started this medication and went through all the big things to watch for it was indicated to us that anything about 70ish was getting high and that we would have to closely monitor her to ensure that her body was metabolizing efficiently as she also has always had mobility issues and chronic GI problems. With all this new information we started researching better, safer, options for Lily. That is when we found the world of Cannabis and all the beautiful faces it was currently saving.

Suddenly we caught a break, or so we thought. We couldn't wait to bring this new information we found on the Internet to our Neurologist. He informed us that he was picked to lead a medical trial treating Dravet patients with CBD oil. He was very excited and let us know that he immediately thought of Lily and that it would probably take a week or so to get all the paperwork finalized. A week or so turned into a months and meanwhile Lily was constantly in and out of the hospital.

We finally decided we could no longer wait, and we made the decision to move her to Colorado where she would have full access to all Cannabis treatments.

We would have never made it here if it were not for the generosity and compassion of not only family and friends, but mostly complete strangers. Lily's story was featured on two separate local news stations and Yahoo news. By the next morning we had reached our goal to move.

We arrived in Colorado the day before Mother's Day and what a gift it was! Within the first few days of starting Haleigh's Hope, we saw a dramatic reduction in her seizures. Then the most amazing thing started to happen, we began noticing this tiny voice, chiming in here and there. Lily was considered non-verbal when we moved because she could repeat what you said to her, but she couldn't actually formulate her own thoughts. All of a sudden we had this hilariously outspoken chatter box, who made it very clear that she had retained many words over the years and despite not using it, she had a very diverse vocabulary. We quickly learned to watch what we say and spent many hours trying to correct her language. All our hardwork was worth it to hear her beautiful voice. The first few weeks we played the I love you game for hours!

Hearing "I love you more" was the greatest reward for the risk we had taken not knowing if Cannabis was really going to work or not. We were finally meeting our daughter Lily. It was like witnessing a miracle.

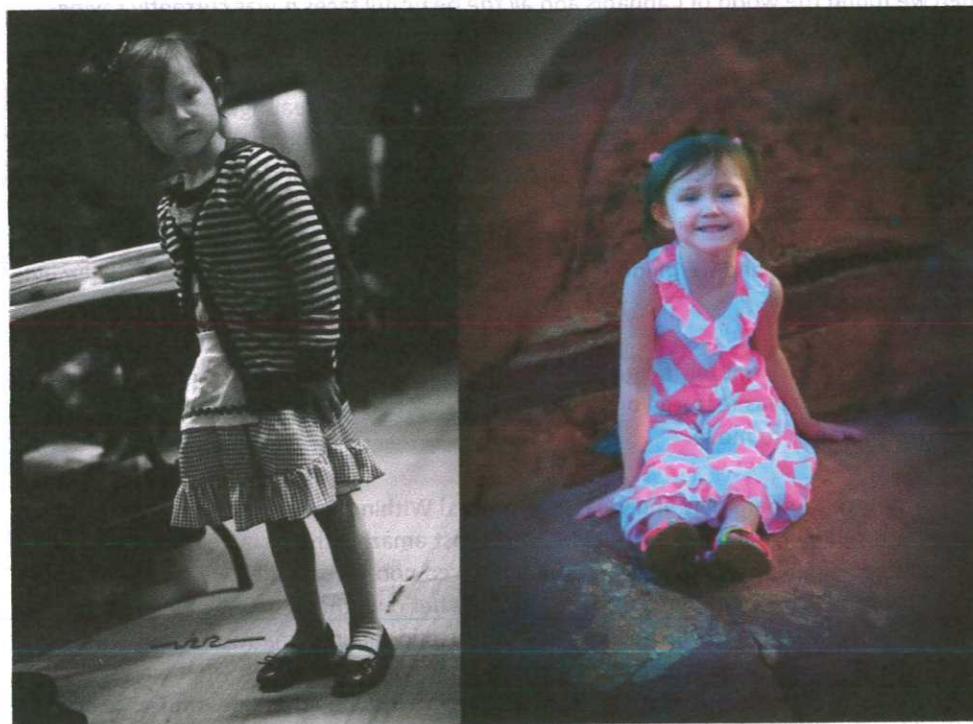
We began weening the Depakene pretty much right away and by the time she was completely off of all pharmaceuticals and only on Haleigh's Hope Lily experienced over two full weeks of seizure free days! It was then we knew until the laws were changed to allow us to return to our home in WI, Colorado was now our home.

Since starting Haleigh's Hope in May Lily has had over 80 days of no seizures and now speaks in full sentences. Lily sings, dances, and is enjoying her new life as a 4yr old little girl not plagued by back to back seizures. How can anyone doubt that Cannabis is Medicine. It saved our little Unicorn. Lily was never supposed to take her first breath, let alone dance in her first pow wow, be crowned in a pageant, climb the balancing rock at Garden of the God's, travel across the U.S. in a Uhaul and the greatest of all being able to tell her Mommies exactly what her thoughts on the world around her is and to hear her say that she loves us everyday.

**Cannabis Is Medicine, just ask Lily!**

**Cannabis is now Lily's Hope and the Hope of all the children & adults like her. It's time we legalize it so everyone can have Hope just like our Lily.**

**Light & Love,  
Vicki Pletka &  
Rosalinda Wirth  
Lily's Mommies ♡**





11/22/2015

**We are asking that you please vote to amend Bill 961.14 Lydia's Law so that we may be able to easily and freely obtain and administer CBD oil to our son, Jacob, without any barriers.**

**Jacob has suffered from epilepsy for nearly his entire 9 years of life. It is an extremely frightening and draining ailment, one which we would like to improve for him.**

**We also have been considerably affected by the number of children that were not given the chance to try the oil and are no longer here and never WILL get that chance. It is devastating and we would like this Bill amended in their honor.**

**Please do the right thing and help so very many... allow us and countless others to administer without barriers.**

**Respectfully,**

**Jen, Jeremy & Jacob Schultz  
1639 Victoria Drive  
Waukesha, Wisconsin 53189  
Schultz@wi.rr.com**



November 23, 2015

I can't even begin to explain what life has been like the past 19 years for my son and me personally. Trying to keep Jake comfortable every hour from the seizures he suffers through daily. Jake was our first born child, and as you can imagine you're happy and excited to start your family with you're first born.

Jake was nine months old when we started to notice some movements that didn't seem like normal baby movements. After seeing our Doctor along with others at Children's Hospital we received the diagnosis of Epilepsy, and a quite severe case of it called Lennox Gastaut Syndrome, which is a rare and often debilitating form of childhood epilepsy. This type of Epilepsy causes intellectual functioning, uncontrollable seizures, behavioral problems that lead to acute psychotic episodes, character problems, and irritability. Google Lennox Gastaut Syndrome and you will see how devastating this syndrome is.

Jake has failed 18 FDA approved Epilepsy Medications, the ketogenic diet three times, along with the Vagus Nerve Stimulator Implant. Jake is also not a surgery candidate due to his seizures being generalized all over his brain.

What are my options after 19 years of trying to have quality of life for my son? What about quality life for myself, my other son, and my marriage? Jake needs constant supervision 24 hours a day due to his Epilepsy, which has caused him to be non verbal, in diapers, in ability to feed himself at times, attention span of 2 minutes with any given opportunity to learn, and supervision of his aggression issues because of his Epilepsy. Can you imagine what this type of life is like for any human being? Jakes life is being at home and having a routine going to a special needs school, which is coming to an end at the age of 21. Do you know my options are few for after age 21 due to his aggression issues of uncontrolled seizures? I have done my research, and not many quality programs will accept Jake due to his medical condition and aggression from his Epilepsy here in WI. Again I must stress where is the quality of life for everyone involved?

Jake is up by 3:00 AM every morning due to heavy seizure activity. So our day starts at 3:00 AM and if were lucky ends by 9:00 PM. Jake has about 20-30 seizures a day that we physically see, not to mention the ones we don't see that are subclinical going on in his brain. If we're lucky Jake has a Tonic Clonic convulsive seizure weekly. This takes two people to help him through this seizure, because one needs to hold him while the other cleans him up from urinating all over himself and whatever he was lying on. Again I ask where is the quality of life?

About three years ago now I can recall seeing the CNN special of Charlotte Figi and the miracle CBD oil did for her. I was so happy to hear the success of even one child that could be helped by this oil nobody should have to live a life like this and watch someone suffer like we do. Almost 18 months later and we still are not able to have the oil here in WI. Again I ask where the chance is of a quality of life.

I am an exhausted worn out mother who cannot watch my son suffer from dizziness, tremors, hair loss, blurred vision, insomnia, urine problems, liver failure, depression, constipation, more seizures, aggression from medication, disorder of pancreas, bruises and pain in his stomach. This is a list of all FDA approved medications my son has been on. Again I ask where is the chance of quality of life?

Thank you for listening to my journey and I hope we get the chance to at least try and see if quality of life can be better for Jake.

Sincerely,

Sherri Kroening  
N95W25867 Riverview Drive  
Colgate, WI 53017

Neurology, Froedtert Hospital  
9200 W Wisconsin Ave, 2nd Floor  
Milwaukee, WI 53226  
414-805-8710

October 6, 2015

Re: Jake M Kroening  
N95w25867 Riverview Dr  
Colgate WI 53017

To Whom it May Concern,

Jake Kroening is under my care for symptomatic generalized epilepsy (Lennox-Gastaut Syndrome) with a known 22q11 duplication. Mr. Kroening also has a history of developmental delay, autism, and aggression. He is non-verbal, has an unsteady gait, and requires significant assistance to complete activities of daily living.

Mr. Kroening has tried and failed multiple antiepileptic medications as well as a vagal nerve stimulator to try to decrease his seizure activity. Patient is currently taking several medications, but continues to have breakthrough seizures and aggressive behavior that greatly affects his quality of life. He was last seen in my office 6/16/2015 at which time he was taking Depakote and Vimpat.

If you have questions regarding Mr. Kroening's condition, please feel free to contact my office at 414-805-2656.

Sincerely,



Chad Carlson, M.D.  
Associate Professor of Neurology  
Medical College of Wisconsin  
Co-Director - Comprehensive Epilepsy Program

11/23/2015

## **Hello Hearing Committee,**

Thank you for taking the time to be at this hearing to hear our stories and to potentially help our families.

Our daughter, Lydia who is 21, had her first seizure (or the first one we saw) just before she was 7 months old. Up until about 18 months of age she was progressing normally and hitting all her milestones. As her seizures increased and the parade of seizure medications went on, her cognitive ability decreased, she lost her speech, she became pretty lethargic and her behavior became more of an issue. At the age of 16, she was diagnosed with Dravet Syndrome.



She is currently on 4 seizure medications and having one to two seizures pretty much every night. She is on Depakote, Keppra, Phenobarbital, and Potiga. We have tried: Tegretol, Neurontin, Onfi, Ativan, Zorontin, Klonopin, Lamictal, Gabitril, and Topamax. She was also on the ketogenic diet for almost 3 years, with limited success. When she was 6 she had the Vagus Nerve Stimulator implanted. It is hard to say if this is beneficial since she is still having seizures.

In the spring of 2014 she started Stiripentol, which is a drug from Europe and has seen some success with Dravet patients. It took us almost a year of paperwork to get it and we did have such high hopes. Well, after being on it 6 months we discontinued it. Her seizures did not improve and her sleep was totally messed up. She was up and down all night, and as a consequence, so were we. She is finally once again sleeping through the night, except when she has seizures.

In 2007 we had to get a feeding tube placed for Lydia. She refused to eat or drink anything. Since then she has gone from not eating to eating about three times, lasting from about 6 months to a year. As I write this she is in a non-eating phase which has been going on for over a year. We think all the medication is affecting her appetite.

Lydia is totally dependent upon us for care and always will be. It is heart breaking to watch her having seizures. We have had a tough road. If there is something out there that could stop or greatly reduce her seizures we would love to have access to it. Kids everywhere would love to have access. What is also heart breaking is knowing that if we could have stopped these seizures when she was younger she may not be so cognitively delayed today. There are young kids out there seizing at this very minute who could potentially have a better outcome than Lydia.

**We are begging you to pass this amendment to Lydia's Law.**

Sincerely,

Edward and Stephanie Weisse

3360 Town Trail, Brookfield, WI 53045

262-781-7652



November 23, 2015

These are our sons Thomas (13) and Seth (11). Our son, Thomas, suffers from intractable epilepsy. This means we have yet to find a medication or combination thereof that controls his seizures. Thomas had his first seizure when he was 10 months old. The last twelve years have been a journey of multiple neurologists, medications, tests, scans, hospitalizations and even brain surgery. None of the medications or the surgery have brought relief from the seizures. None of these decisions have been easy. Many things about this journey are not easy, the least of which watching your son have seizures and not being able to stop them. My son currently takes a combination of five different medications per day. We are running out of pharmaceutical medications to try.

Our family went to the Capitol in February of 2014, to show our support of CBD oil. I was able to speak at the hearing and share our story. That night my son, Seth, asked me 'why can't Thomas take the medicine they talked about today'. I had no good answer for him then, and I have no good answer for him now.

We urge your support.

Respectfully,

Jon & Jenny Godin  
S15W37284 Willow Springs Drive  
Dousman, WI 53118  
(Waukesha County, Town of Ottawa)

# Meghan Bertram 19

## Biggest loss, her voice in 2006

*"I want to be able to talk to my friends"*

(spelled on 26 letter board that takes over 4 minutes to spell)



### Other Interventions:

**Modified Atkins Diet** - Could not function, slept all the time

**Ketogenic Diet** - No change in seizures

**VNS** - Turned off 3 years ago and no seizure reduction.

**Brain Surgery** - Eradicated her starring seizures but had debilitating affects with regards to motor skills, swallowing, left side neglect, vision and drop foot.

At this time meghan requires **24 care** for seizures, safety and her communication. She will require a 1:1 for her job and programs that she will work toward in the adult world.

Meghan wants to tell this hearing: "MOST TIMES I FEEL SLEEPY AND MAD ABOUT WHAT I HAVE LOST. NOT TALKING IS THE BIGGEST LOSS. I THINK THAT EVERYONE SHOULD GET THAT CHANGE. THE DRUGS MAKE ME HAVE HORRIBLE SIDE EFFECTS. PLEASE PASS THIS AMENDMENT!"

**Jennifer and Meghan Bertram W292N6880  
Dorn Road Hartland, Wi 53029 262-366-4604**

### Meghan has tried 14 Seizure Drugs:

\* **Lamictal** - slower processing

**Depakote** - Became incontinent at night

**Topamax** - Dopey, drooling, unable to feed self and cognitive regression.

**ACTH** - Lost her speech and never regained.

**Felbatol** - Lost her appetite and 20# in 1 month

\* **Keppra** - Excessive hyperactivity, unsafe, jumping off dressers

**Zonegran** - no seizure control.

\* **Chlorazptate** - Extreme lethargy This drug is a benzodiazapene and is highly addictive.

**Phenobarbital** - Excitability and stopped working all together.

**Banzel** - Increased seizures and weekly status (when seizures don't stop and require emergency medication)

\* **Vimpat** - Dizziness

**Clonazepam** - Excessive irritability and aggression.

**Valium** - Lethargy and stopped working.

**Onfi** - Excessive aggressiveness to self, others and properties. She would head butt the drywall and create holes.

\*Still on at this time

What would you do if you had a child that experienced hundreds of seizures a day? Now imagine that after many medications (some tried twice), steroid treatments, surgeries, vagus nerve stimulators implanted and explanted, vitamin supplements, rescue medications that have to be injected rectally, hundreds of trips to the emergency room, countless stays in the hospitals, IV's full of loaded medication doses and on and on....NOTHING works for that child! What would you do? How would you handle it? What kind of quality of life would you or more importantly, would your child have??



This is a reality that is facing a very close friend of mine. Kari has a child that has experienced exactly what I mentioned above.

Her daughter Haily had her first seizure at 6 months of age. She received a diagnosis of Epilepsy at the young age of 1 and an even more serious diagnosis of Lennox Gastaut Syndrome at the age of 2. Lennox Gastaut (LGS) is a severe form of epilepsy. Seizures usually begin before 4 years of age. Seizure types, which vary among patients, include tonic (stiffening of the body, upward deviation of the eyes, dilation of the pupils, and altered respiratory patterns), atonic (brief loss of muscle tone and consciousness, causing abrupt falls), atypical absence (staring spells), and myoclonic (sudden muscle jerks). There may be periods of frequent seizures mixed with brief, relatively seizure-free periods. Most children with Lennox-Gastaut syndrome experience some degree of impaired intellectual functioning or

information processing, along with developmental delays, and behavioral disturbances. Lennox-Gastaut syndrome can be caused by brain malformations, perinatal asphyxia, severe head injury, central nervous system infection and inherited degenerative or metabolic conditions. In 30-35 percent of cases, no cause can be found. There is usually no single antiepileptic medication that will control seizures. Children who improve initially may later show tolerance to a drug or have uncontrollable seizures. The prognosis for individuals with Lennox-Gastaut syndrome varies. There is no cure for the disorder. Complete recovery, including freedom from seizures and normal development, is very unusual.

LGS has not only robbed Haily of her development, caused hundreds of seizures daily and stolen countless hours in recovery or hospital visits, but it has also caused Kari fears that no parent should have to face; that is...how long will my child live. Haily has not been responsive to any of the treatment options listed in my opening paragraph and continues to seize daily; for 18 years now. Imagine what her quality of life is!

I'm sure you can understand how excited and hopeful Kari became after hearing about a treatment for intractable epilepsy like Haily's that was being used in Colorado; Charlotte's Web; Charlotte's Web is a sativa marijuana strain that has gained popularity as a good option for treating seizures as well as a range of other medical conditions. This medical potency is due to its high-CBD content, which was specifically cultivated by Colorado breeders The Stanley Brothers for a young epileptic patient named Charlotte.

As you know, the legal use of the CBD-Oil is currently being examined in Wisconsin through bill AB726. Would you PLEASE consider supporting this bill and helping patients like Haily who may never know what a seizure free day is? From one parent to another; imagine if your child suffered like Kari's

does? Wouldn't you want to give your child the quality of life that EVERY child deserves??

If you would be at all interested in meeting or talking to Kari and Haily, she has asked me to pass along her information. She can be reached at [414-840-5051](tel:414-840-5051) or [karikrause@wi.rr.com](mailto:karikrause@wi.rr.com). In the meantime, I simply ask that you look into this bill and imagine what a difference the CBD-Oil could make in the lives of SO many who are suffering.

Thank you for your time and consideration.