



us they likely would not live to age 1.

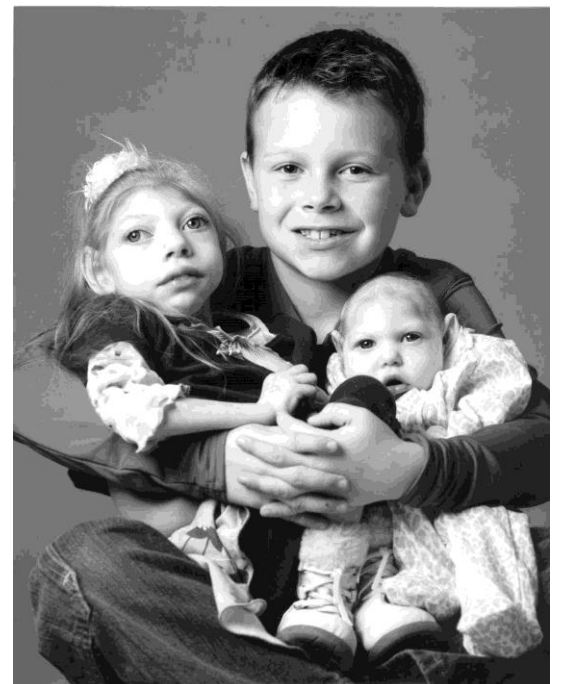
My name is Gwen Hartley, and I am the mother of Cal (20), Claire (forever 17), & Lola (12). Both of our daughters were born with a very rare neurometabolic, genetic condition called Asparagine Synthetase Deficiency. They are 2 of only 25 known cases of this condition worldwide. They have profound special needs that result in cerebral palsy, seizures, global developmental delays, dwarfism, hip & shoulder dislocations, scoliosis, kyphosis, feeding difficulties and more. Doctors told

We have watched our girls struggle with seizures and tone for 12 and 17 years, respectively. On December 17, 2018, our daughter, Claire, passed away unexpectedly. We were never given a cause of death, only possible ideas as to why it could have occurred. We were told that even an autopsy would not give us answers. One possibility is SUDEP (Sudden Unexpected Death in Epilepsy), which is something both girls are more prone to, due to their neurological condition. We are completely heartbroken & devastated by this loss. It has changed us, and we will never be the same. Claire was our strong, healthy girl! We cannot lose Lola now, too. I am not certain how a parent could ever survive this loss not once, but twice.

We have had an unusual situation with our girls due to their ultra-sensitive bodies/systems. We are unable to use medications or any pharmaceutical drugs because they cause our girls to seize. Tylenol & Benadryl are fairly benign, over-the-counter medications, yet they cause near constant seizures for Claire & Lola. As a result, we've been forced to use more natural treatment options with our girls such as vitamins, minerals, supplements, herbal tinctures, essential oils, applied kinesiology, craniosacral therapy, hydrotherapy, hippotherapy, and more. We attribute their length of life to the fact we didn't stress their systems further by using Rx drugs. Their doctors are in agreement.

We beg you to give us the chance to try low THC CBD oil with Lola. More than ever now, we feel the urgency, & it's all-consuming. There is no other reason I would be pouring myself into passing this law just two months after the death of my child except to save the life of one of my other children. This has been a struggle, but I will do ALL I CAN to save Lola's life. Low THC CBD oil could potentially do just that.

On January 26, 2015, the American Academy of Pediatrics (AAP) updated their position regarding the use of cannabis with children who have debilitating



conditions. They stated, "...given that some children who may benefit from cannabinoids cannot wait for a meticulous and lengthy research process, the Academy recognizes some exceptions should be made for compassionate use in children with debilitating or life-limiting diseases."

<https://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/American-Academy-of-Pediatrics-Reaffirms-Opposition-to-Legalizing-Marijuana-for-Recreational-or-Medical-Use.aspx>

Furthermore, the Epilepsy Foundation states that, "When conventional treatments do not work to control seizures, as is the case for roughly 30% of people with epilepsy, it is not unreasonable to consider CBD oil. However, this should only be considered after a thorough evaluation at a specialized epilepsy center to look at whether all possible treatments (including FDA-approved new and add-on medicines, dietary therapy, devices, and surgery) have been reasonably tried. The Epilepsy Foundation urges anyone exploring any treatment for their epilepsy, as permitted under their state law, to work with their treating physician to make the best decisions for their own care. "

<https://www.epilepsy.com/learn/treating-seizures-and-epilepsy/other-treatment-approaches/medical-marijuana-and-epilepsy>

<https://www.ncbi.nlm.nih.gov/m/pubmed/850145/> ~ This article was written in April of 1977 and states that "CBD was an effective and relatively potent anticonvulsant." We have known for 42 years that CBD is medically beneficial for those with epilepsy. 42 years!

In addition, many other health conditions can be helped by the use of cannabis. The most comprehensive list of conditions with accompanied research studies can be found at the following link: <https://www.theroc.us/research-library>

One of the most important aspects of this low THC CBD oil is independent third party lab testing. This would help to ensure that the products bought are safe, effective, and contain exactly what they claim to contain and nothing else. These products are tested for potency, terpenes, residual solvents (butane, heptane, hexane, petroleum products), pesticides & microbial contamination (bacteria, yeast, mold, E.coli).

In May of 2018, the CDC reported that 52 people were sickened by fake CBD oil in Utah. These products claimed to contain CBD but instead contained synthetic products that led to a variety of illnesses. The CDC urged states to regulate products more closely in order to avoid this occurring again. We cannot take this risk with Lola, as it could be life threatening for her, due to her extreme medical fragility.

<https://www.cbsnews.com/news/52-people-sickened-by-fake-cbd-oil-in-utah/>

Moreover, even the FDA is concerned about CBD products not containing the amount of



CBD the bottles claim to contain and have issued warning letters to these firms and consumers as well.

<https://www.fda.gov/NewsEvents/PublicHealthFocus/ucm484109.htm>

On February 24, 2016, the FDA released the results from the above studies that they wrote warning letters about. Only 2 out of 24 CBD products from 8 companies actually had the amount of CBD listed on the product label. Some contained 100 times less than the label claimed. Several contained zero CBD. We need consistency & safety. We need products we can trust. Many of the families using these oils are trying to help their children with disabilities or others with debilitating conditions. To have no CBD present or excessive levels of mold, solvents or pesticides present puts a lot of trusting parents and vulnerable children at risk. Having third party lab tests would eliminate that risk. Remember, the FDA doesn't regulate CBD products, as they are considered supplements.

<https://www.newhope.com/botanicals/fda-finds-only-2-24-cbd-products-have-what-they-say-they-have-them>

In legal states, cannabis is regulated more closely than our produce in grocery stores, many/most times even with video monitoring. It is tracked from seed to sale, and the testing is quite extensive. Please see Ryan Treacy's written testimony for detailed specifics on the need for third party lab testing. We wrote this requirement into Claire & Lola's Law for safety and to ensure that what is bought contains what it claims to contain. This protects our children from harm and is a crucial aspect of this bill.

At this point in our lives, protecting our child's life and giving her every possibility to live a full life is our priority. Our three children are the lights of our lives. Our daily activities revolve around them. Though our girls have never spoken a word, they communicate volumes, and their smiles tell us they are happy. We have been passionate since day 1 about not letting their disabilities prevent us from letting them live life. We are proud of the fact that they've visited many states, including Hawaii twice, and been able to go boating, fly on planes to the beach, hike in the mountains, swim in lakes, ride horses, go to Chicago and experience the big city, enjoy the deserts of Arizona, lounge on a beach chair in Florida, & attend hundreds of basketball games watching their big brother play. We are so proud to be their parents, and losing Claire has positively shattered our lives in a way we could never fathom. That is why we are so passionate about this bill. It's a way we can help our child & give her the best life possible for as long as possible! This could be our lifeline.



You may wonder why we don't just use Marinol (synthetic THC) or Epidiolex (purified CBD) to help control Lola's seizures. First of all, Marinol is synthetic, and our girls cannot handle synthetic medications at all. It is as if their bodies don't know what to do with it except to react negatively (usually by seizing). Second, Marinol has actually been known to worsen & cause seizures, impair cognition, and cause cardiac disorders. It also can cause nausea, vomiting and abdominal pain. Our 14 lb., 12-year-old daughter cannot afford to suffer through any of the above complications, as they could be catastrophic for her health & life. Third, Marinol contains other inactive ingredients which Lola is allergic to, so we would not be able to use it with her. And technically, Marinol is never prescribed for epilepsy anyway.



Epidiolex is a pharmaceutical drug which contains sesame seed oil (one of Lola's allergens), sucralose, and artificial strawberry flavoring. It commonly elevates liver enzymes (which is already an issue with Lola), it causes insomnia & sleep disorders (which is already an issue with Lola), it causes decreased appetite & weight loss (which is already an issue with Lola), and it also frequently causes anemia (which Lola has almost died from twice). It increases risks for contracting infections & viruses, it causes fatigue and lethargy, and it has been known to cause rashes (which we battled with Lola for two years & just figured out recently). In addition, it frequently causes drooling and increased salivation which can lead to pneumonias and early death. It is only effective for two types of intractable epilepsy, and Lola does not have either type.

<https://www.abc.net.au/news/2018-07-05/epilepsy-treatment-cannabis-chemical-thc/9944878>

The above article details why it's essential to have low THC CBD oil vs. just CBD. In order to fully extract the THC from a plant, solvents such as butane, heptane, & hexane are used. They leave a residue in the oil which is not safe for my daughter to consume and could actually worsen her overall health. Having tiny amounts of THC actually allows for the "entourage effect" to take place. This means that CBD works hand-in-hand with THC, reducing its negative effects and increasing its benefits.

The article also does a cost comparison between the low THC CBD oil compared to Epidiolex, and the results are startling. Using cannabis oil would cost roughly \$10/day or \$270/month or \$3240/year. Using Epidiolex, which would not be covered by insurance, would cost

\$160/day or \$1100/week or \$60,000/year, all out of pocket.

Key points about Claire & Lola's Law:

- This bill legalizes nothing.
- This bill is conservative.
- This bill is PRO-LIFE!
- This bill is in alignment with Kansans' conservative, Christian values.
- There are zero recorded deaths from cannabis in the last 12,000 years. Opioid drugs cause an average of 72,000 deaths per year. Alcohol causes 88,000 deaths per year.
- The cost to Kansas for Claire & Lola's Law = \$0
- This bill is not about cannabis or marijuana.
- This bill is about doing the right thing for kids who are suffering.
- Kids aren't criminals! This bill simply allows families who have exhausted all conventional routes one more option to save their child's life.
- Low THC CBD oil does not cause users to get high, & these oils aren't addictive.
- These oils cannot be abused even if the entire \$150 bottle was ingested. They are innocuous and would cause diarrhea but no "high," even in that quantity.
- Claire & Lola's Law cannot be abused.
- Nearly identical laws are in place in Alabama, Georgia, Virginia & Delaware, and none of them have been abused or had any kind of negative impact to those states whatsoever.
- Claire & Lola's Law will have a cost savings for our Medicaid system, as there will be fewer doctor visits, fewer ER visits, and a decreased use of prescription medications.



I wanted to share something written in support of Carly's Law driven by Spirit of Compassion (State Rep. Mike Ball) Special to AL.com on March 03, 2014, as I feel it is completely relevant to Claire & Lola's Law as well...

"Carly's Law is a spiritual issue, not a political issue. It is clothed in the Spirit of Compassion. I never thought of Compassion as a powerful force until I started working on Carly's Law. It has led me to really comprehend the ramifications of the shortest verse in the Bible, "Jesus wept." Since I started this journey with Carly's Law, I have struggled with uncontrollable tears.

Although I have been an active participant in formulating, sponsoring, and promoting "Carly's Law;" in many ways I have been more of a spectator as I watch the power of Compassion do the heavy lifting of changing hearts. Jesus was clothed in Compassion when he raised Lazarus from the dead, healed the sick,

and opened blinded eyes. I believe it was even Compassion disguised as Anger that compelled him to overturn the moneychangers' tables in the temple.

Politics is a messy business that gets even messier during election season. Our form of government makes it inevitable. I strongly suspect much of the messiness was intentionally built in by our Founding Fathers as a means to keep powerful forces in check. But it has unpleasant side-effects.

Legislators are bombarded on all sides by many individuals and groups with many needs, opinions, ideas, pleas and demands. We squabble among ourselves. We are often surrounded by chaos and confusion. As we search for clarity among the confusion, we sometimes get defensive and hard-hearted. It's not because we're cruel and don't care; it's just human behavior.

If Carly's Law is successful, it will not be because its supporters yelled the loudest, sent the most cut-and-pasted emails, or had the most money. It will be because its supporters are driven by Compassion. Compassion for suffering children. Compassion for their families who suffer with them. Compassion for our adversaries. And even Compassion for legislators. Compassion that makes hard hearts tender. Compassion that cuts through the chaos. Compassion that makes me and Jesus cry."

~State Rep. Mike Ball represents the 10th District in North Alabama

In loving memory of...

Claire Elise Hartley

Born on July 25, 2001 ~ Gained her angel wings on December 17, 2018

