



My name is Amy Young, and our daughter Eleanor (Leni) was 34 days old when she had her first CT scan. We discovered that she had a massive stroke before she was born, and it destroyed all of her brain except for her brain stem and a small strip of frontal lobe. We knew she'd eventually have seizures to go along with her cerebral palsy, hydrocephalus, microcephaly, and the dozen other diagnoses Leni was given.

Seizures started when she was 7 months old, and within hours, Leni was inpatient at Children's Hospital of Alabama. They tried to get her seizures to stabilize without success and then advised us it was time to call in hospice. The palliative care doctors even had the beginning of a discussion about "withholding nutrition" to "end her suffering." We told them that wasn't an option. Just days before, we had a happy, sweet, bubbly baby, and now she was motionless and couldn't even make a sound due to the extreme doses of anti-seizure

drugs that were given to her. We chose to take our sweet baby home and savor every moment we had left with her. We learned over time to gauge her mood and needs by the sound of her breathing. Leni's seizures were awful. She had dozens of them every single day. There were so many that we didn't even count the little ones.

Leni was excluded from the Carly's Law CBD study at UAB that our family fought so hard to make a reality. She was already on adult doses of 3 powerful drugs: Klonopin (.5 mg daily), Phenobarbital (81 mg daily), and Diastat (up to 20 mg daily). These were considered the last resort combination of anti-epileptic drugs. The study took into consideration the numeric amount of drugs children used, not the dosages.

Our family was left with the options of either continuing to keep treating her in Alabama and wait for that one catastrophic seizure that would eventually take her life or move to a state with more legal options available to her. We moved.

We left behind Leni's older brother and sister who were both still in college, all of her doctors, therapists, grandparents, great grandparents, and all of our friends. Our family became one of the many "Medical Refugee" families, seeking treatment unavailable in the state in which they live. We drove across the country from Alabama to Oregon since Leni was unable to fly at that time due to seizing nonstop. We drove almost 3000 miles and spent 1 week on the road, with Leni seizing the entire time, just so we could give her a chance to live.

Leni started taking cannabis oil in the summer of 2015. Within an hour of her first dose, she could focus on us and see better than she had ever before. Within a week, she was holding her own head up watching Frozen. Leni had 5 seizures total between the 3rd and 5th month of beginning her oil. Total. In Alabama before starting the oil, 5 seizures before breakfast would have been considered a good day. Leni's been able to progress beyond anything we've been told was a possibility for her. She existed in her own world before, and now she's engaged and completely aware of everything in ours! We even have to spell some words around her now ("pudding," "ice cream," "banana")! That first Christmas in Oregon was the first time we were ever able to shop for TOYS that she can play with!

Now, 3 years later, life is vastly different – not only for Leni, but for our entire family. We are no longer house-bound for weeks and months on end as we were before. Something as simple as a change in barometric pressure or flashing Christmas lights would send Leni into seizure clusters before her oil. We have been able to take vacations together, fly across the country for college graduations, attend weddings,

spend time with family members & friends, sled on mountains, hike through state and national forests, camp in the Painted Hills, and finally enjoy Christmas lights from Thanksgiving through the New Year! We no longer worry about where the closest emergency room is, and we don't even worry if we're somewhere without cell service. This is incredible considering we bought our home in Alabama because it was 1/2 mile from the hospital where the life flight helicopter was stationed. Our family's life has blossomed beyond what we ever imagined was possible, along with our sweet girl.

Leni has been able to reduce 2 of her pharmaceutical drugs, 70% and 75% respectively, and we've been able to wean her off of the 3rd drug completely. In 2017, she had a total of 1 seizure. We have had zero ER visits since she began her oil. Our once silent and still daughter is now talking nonstop in her own language; in which she communicates extremely effectively. We learned quickly that Leni understands and processes language. She now uses a computer that she can control with her eyes to play games and to help her to communicate.

Through the passage of Leni's Law in Alabama, I've been able to be a small part of many families' lives. As Leni's mother, they frequently share with me their milestones because they know that I fully understand the magnitude of these changes we're all seeing. I've been able to see children with seizures triggered by water learn to swim. I've witnessed a girl who was once institutionalized and considered "unreachable" now come home and become "teachable," in her teacher's words. I've seen a wife in the final stages of Alzheimer's finally be able to tell her sweetheart, "I love you" once again. Grandmothers who have been battling breast cancer for years are finally getting their appetites back as well as normal blood counts for the first time in years. A man with a traumatic brain injury so severe that his family began oil as a last resort before taking him off of life support is now almost completely recovered both physically and cognitively. A 3-year-old battling leukemia can now avoid opioids & being fed through an NG tube while going through chemotherapy, thanks to this oil. I could go on & on about the people positively affected by Leni's Law, which is extremely similar to Claire & Lola's Law. These spouses, parents and people who are using oil are pharmacists, business owners, scientists, missionaries, military members, legislators, law enforcement officers, roofers, car dealers, American Sign Language interpreters, doctors, stay at home moms, nurses, district attorneys, school teachers, students, and many others. Children who use oil in both Alabama and Georgia can now do so openly with their doctors' guidance. Many have been able to use the oil while inpatient in a hospital in both states.

Everyone in Kansas with a life-limiting condition should have the option to use low THC CBD oil without having to leave their homes, families, doctors and support systems.

What does it say when starving a baby to death is acceptable and legal, but using non-intoxicating, innocuous cannabis oil that has unquestionably saved my daughter's life isn't?

*NOTE: The picture on page 1 shows Leni in 2015 before using cannabis oil (left) & three months after starting the oil (right). The picture on page 2 shows Leni on Halloween 2018.

