




A TESTIMONY
FOR
CONNECTICUT
BILL #5450



Henry Lloyd - Age 6

Good morning honorable representatives and senators of the Committee.
My name is Linda Lloyd and I'd like to start by thanking all of you for listening to my testimony supporting the legalization of medical marijuana for children.

My 6 year old son, Henry, has a primary diagnosis of catastrophic temporal lobe epilepsy. He started having seizures at the age of two, and as time passes his seizures increase in frequency and severity. He has a range of seizure types...most often generalized tonic clonic seizures. These are the scariest ones by far. Without any warning, Henry will instantly drop face forward and start having convulsions. He cannot break his fall and unfortunately his face is what bears the impact resulting in injuries. His seizures last an average of 3 minutes during which he convulses and stops breathing, often turning blue. I can say as a parent, this never gets easier. With every seizure, I feel the same gripping fear that this is the one that won't stop. That this is the seizure that will take my son from me forever.

Henry has tried 13 different pharmaceutical medications, sometimes taking five prescriptions at one time. He has tried the Modified Atkins Diet and the Ketogenic Diet, only to have his seizures double. None of these treatments were successful, and therefore he is considered refractory. Like Henry, nearly 1/3 of people who are diagnosed with epilepsy cannot be controlled with pharmaceutical medications. Henry swallows 21 seizure pills per day. 21.

The side effects of these medications, especially the benzodiazepines, are as devastating as the seizures themselves. Some side effects include anxiety, depression, self harm, aggression, cognitive slowing, and hallucinations... just to name a few. And with these medications Henry continues to decline, having more and more seizures. It has had a profound effect on his health, memory, behavior, cognition, and development.

Without other treatments available, it would *seem* Henry's last option is invasive brain surgery. Removing almost half of his brain, as well as dividing the two hemispheres, would be only palliative in his case, and not curative. Doctors are gently trying to manage our expectations, reminding us that the seizures will not stop. Their hope is to maybe slow down the seizures and therefore possibly the cognitive decline as well. I find it horrific that this seems to be all that is left to improve our son's quality of life.

But through diligent research, I know that this is not the case. I have exhausted every possible option, *except* for one. And that's medical marijuana. It is a viable and often very successful treatment for epilepsy, even those with difficult to treat seizures. The side effects of cannabis are mild in contrast to the pharmaceuticals. "Someone in the US dies every 19 minutes of a prescription overdose, often accidental. I have yet to hear of ANYONE dying from a marijuana overdose." (Dr. Sanjay Gupta).

How can Henry and children like him not be afforded the opportunity to at least try this as a treatment, to possibly stop or reduce their seizures, their seizure meds and the side effects that go with them. It's estimated that up to 50,000 people die each year from epilepsy and seizure related causes. Every week in the seizure community, I read of someone lost to epilepsy. But multiple times a day, I also hear the success stories. Children who have tried everything else have stopped or greatly reduced their seizures using medical marijuana. Many of them at the same time make huge strides in development and cognition as a result.

I grew up in Connecticut. My family is here... my friends...my support system, and what I view as the best school that Henry could possibly attend. Please support legalization for Henry and all of the children like him. Please don't force me to move out of state and leave my home in order to give my son a fighting chance. Thank you for your time and consideration.

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