

Raised Bill Number 5450 – AN ACT CONCERNING THE PALLIATIVE USE OF MARIJUANA

Sean William Hearn's Testimony
Age 10

My name is Jennifer and I am very good friends with Kim Hearn who is the proud mother of Sean W. Hearn. Sean is a 10 year old boy who has been fighting for his life since he was 5 months old. Sean is living with a very rare and debilitating form of childhood onset epilepsy called Lennox Gastaut Syndrome. Children with Lennox Gastaut Syndrome typically suffer with multi and intractable seizure types. Sean has over 50 seizures a day!

Although Sean is 10 years old, developmentally Sean is at 6 month level. He is completely dependent on all of his care. Sean is confined to a wheelchair, he is unable to sit without someone holding him or stand without equipment. Sean is unable to speak. Sean is feed via a feeding tube and takes a combination of 5 seizure medications 3 times a day.

Over the course of the past 9 and half years we have seen multiple doctors and have worked with Yale, Boston Children's Hospital, CCMC, NYU and John Hopkins. We have tried to control Sean's seizures through diet (Ketogenic Diet), medications and alternative therapies. With the onset of puberty rapidly approaching (which typically makes treatment even more difficult) we have exhausted all options and I am terrified for my son.

With the number of medications Sean's takes daily there are side effects. The most notable are extreme fatigue and loss of personality. With every new med we add we lose more of Sean. I have not heard my son laugh in 8 years!

The work that is being done with cannabis oil (which contains no more than 0.3% THC) in Colorado and across the country has given families like mine a reason to hope.

Sean is the most important thing to her. Every decision she makes directly impacts his health and quality of life. She research's everything before considering new treatment options and does not take the subject of cannabis oil lightly. She does not know if she will ultimately make the decision to use cannabis oil as a treatment option for Sean. That is a decision that her and her husband will need to make with Sean's medical team. I ask you to legalize cannabis oil for minors, so that this can be a treatment option here in Connecticut. Please give her son a fighting chance. Please give her the right to choose.

I implore you to pass this bill. Help her give Sean a better quality of life. Please help her save her sons life!!!

With gratitude and hope,

Jennifer Luning
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