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From: Haddox-Wright, Dana <dhaddoxw@visa.com>
Sent: Tuesday, March 10, 2015 6:18 PM
To: JudTestimony
Subject: Testimony - S.B. No. 1064 (RAISED) JUDICIARY . 'AN ACT CONCERNING THE PALLIATIVE USE OF MARIJUANA'

Dear Committee Members,

First of all, I would like to thank the members of the committee for raising a bill that would allow children in need access to medicinal marijuana. I am writing as the concerned parent of a young child with uncontrolled seizures.

Before I get into the details, please allow me to give you some background as to why I am so passionate about getting things changed in Connecticut. I have a five year old daughter who lives with Dravet Syndrome. Dravet Syndrome is a very rare and severe form of epilepsy, which is remarkably resistant to pharmaceuticals. It presents itself within the first year of a baby's life, and begins with prolonged seizures that are difficult to stop. My daughter has been intubated four times and has stopped breathing five times. She typically has absence seizures, but has had all other types (myoclonic, atonic, tonic clonic, etc). Her longest seizure was a grand mal that lasted over two hours. She nearly died from cardiac arrest. She has never had a seizure lasting less than 30 minutes or one that has not required emergency intervention.

Dravet Syndrome affects children in different ways, but most often causes regression of motor and cognitive skills. He/she will have a weaker immune system, which can lead to more seizures, all of which are can be life-threatening. They will have a higher likelihood of dying from seizures. I cannot tell you how many seizures my daughter has had in her five years on this Earth. I can only tell you that I have lost count of her ambulance rides and hospitalizations. I can honestly say that I am in constant fear for her life.

This condition is devastating. Every month, a minimum of one young child dies from this awful disease due to complications. Each month we mourn for these children and their families because we could lose our own just as easily. All it takes is one uncontrollable seizure for my daughter to be taken from us. My daughter seizes no less than once a month despite all of her medications. Right now, she is on three medications and two supplements. She is also on a strict medical diet called the Ketogenic diet, which requires my husband and me to carefully measure all of her meals on a gram scale. All of her treatments wreak havoc on her growing body and internal organs. Each medication comes with its own list of side effects that can range from digestive issues to behavioral problems. There is far more to my daughter's story than I can put onto paper, but I will be happy to send along more information on Dravet Syndrome.

Now that I have shared this information with you, I am hoping you can understand why I believe that a change is needed. Pharmaceuticals have been tried and they are failing. My daughter deserves another option, a natural option that has no proven negative side effects. I am asking for a whole-plant solution that includes not just CBD, but also THC. It has been used in children with Dravet Syndrome and other illnesses in Colorado and has been found to be successful most of the time. It has not been FDA approved but it is giving families hope.

Parents with sick children are so desperate for this form of treatment that they are packing their bags and moving to Colorado in order to give their children a fighting chance. I know of several families in New Jersey, New York, and the Midwest who are relocating. My husband and I do not want to leave Connecticut. We want to raise our daughters here. It is a wonderful and beautiful State. Connecticut laws exclude minors from receiving medical marijuana in any form. According to Connecticut General Statutes, Chapter 420f, Section 21a-408 adult patients receiving medical treatment for a debilitating medical condition may qualify for the State's medical marijuana program. Why are minors suffering from the same or similar conditions excluded when they could receive the same relief? We have to give our

babies and children a chance to thrive when other means of treatment have failed. This would certainly apply to children with cancer, epilepsy, or those suffering from chronic pain or anxiety.

As a parent to a child who would most definitely benefit from the use of medical marijuana, I urge you to consider changing this law. I, along with other parents of children with Dravet Syndrome and other potentially fatal conditions in Connecticut, have only the best of intentions for our little ones. As of right now, we are forced to have them on a daily regimen of pills that do more damage to them than good. My daughter takes 15 pills a day. Many of the children who have access to medical marijuana have been able to decrease their daily medications and/or end them completely.

Thank you all so very much for raising this bill for a change in the medical marijuana laws. My daughter and the other children suffering from Dravet Syndrome who reside in Connecticut deserve better. They deserve more options than what have already been proven to fail.

Thank you for your consideration,

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