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Diane Tarricone (speaker today and parent to West)

Email: drtarricone@yahoo.com, cell 860-617-2848

Cara Johnson Tarricone (parent to West)

Email: massageworks2@yahoo.com, cell 860-617-2847

North Windham, CT

Subject : Bill No 5450

I would like to enthusiastically thank the Public Health Committee for its time and devotion, and for realizing the true need to make pediatric cannabis available in our amazing State of Connecticut.

Our daughter, West Ann Tarricone, twin to Blake Augustino Tarricone, suffers from severely disabling epilepsy. The first seizures came when West was 10 months old. At 11 months of age, West was diagnosed with West Syndrome. Just as West was emerging in childhood, epilepsy took her from us. As Blake grew and mastered milestones, West struggled.

In her short life, West has taken over 16 pharmaceutical medications and tried palliative treatments, several of which nearly killed her. Daily, West also relies on two different rescue drugs, which we carry with us always; Even a 4-minute trip to Blake's bus stop requires that we be prepared to rescue West's life with emergency medication in the event that she stops breathing or experiences other physical failures during acute seizures.

West has 1000's of seizures a day: myoclonics, absence, tonic and tonic clonics. None of the pharmaceutical drugs she was prescribed offers a cure for her epilepsy. And, symptom reduction isn't a fixed relief, as it doesn't allow West to live free of epilepsy for periods of time that benefit her growth. Even with pharmaceutical intervention, West still requires daily "one-to-one" at school, to keep track of her seizures and to provide for vast developmental needs caused by her seizures. Additionally, the school West attends maintains two licensed nurses on staff who administer rescue medications for West when necessary. Because of West's epilepsy, nothing can be left to chance with regard to her day, whether the seizures themselves or the residual environmental risks accompanying them, and this is while she takes presently available, prescribed drugs.

West has "tried it all," medically speaking. It is time she have safe access—with her doctor's approval—to receive prescription cannabis. With this medically safe treatment, West's cognition can improve as her seizures can be dramatically reduced. And, with the correct cannabis rescue medication, West can stop taking heavy doses of valiums and benzos, which further traumatize her body. Her present rescue medications can reduce a grand mal (aka tonic clonic) taking 17-20 minutes to merely slow down the seizure, and while present medications can reduce the seizures escalation, it does not make seizures "go

away.” BUT, with a proper medical cannabis rescue prescription our child could not only stop seizing quickly (30-120 seconds), they could “go away.” West could get back to living her life; she could have a much different life. Potentially, West could experience the same milestones her brother, Blake, has experienced.

As a parent I have researched and studied epilepsy, present pharmaceuticals for epilepsy, and medical cannabis. I have listened to fellow parents of children with epilepsy, who suffer from debilitating seizures, who moved like refugees to states that allow medical cannabis. What I found are amazing stories of success, and formerly debilitated children living invigorated lives. I’ve heard of many children smiling for the first time, saying “Mommy” and “Daddy” and talking, walking and drawing, expressing emotions such as joy and sadness. I have seen changes in other people’s children ALL because of cannabis. I know families that are now medication-free and their child(ren) are seizure-free. I know this is possible for children in our state. I know this is possible for my daughter, West.

I appreciate and applaud this committee for understanding the importance of this medicine and valuing children’s lives that will be greatly improved by this medicine.

****We would like the committee to please consider allowing two caregivers to be able to hold a card on behalf of their child. We also believe that allowing the medicine to be managed by the school nurse in the same fashion current schedule 1 drugs are managed is a reasonable request. West has two schedule one drugs stored at school and that travel in her emergency rescue bag. The protocol would be the same for medical cannabis.*

*Furthermore, should this be approved by the committee and voted on and passed by the house we would hope that it could be enacted under an urgent “clause”, our children just simply do not have time to wait until October 2016 to start getting medicine, they are all suffering daily and need access safely and legally as soon as possible. Thank you so very much.****

Our children need medical cannabis now, in our home state. We are thrilled as parents to know the real potential for this to be legal and safe for our daughter who has suffered enough. Cannabis has successfully eliminated seizures in many children, while also dramatically reducing seizures in others. Cannabis is safely being used by pediatrics in states where it is presently legal. Let us be another safe state. Until it’s approved at the federal level, please pass a state law that allows Connecticut residents to find treatment for our children in our home state, so we might not find ourselves refugees in other states with already-accepted progressive medical legislation.

We support Bill No 5450 . We need action now; our children cannot wait. Please trust in doctors, parents, and growers to work as teams and to make these medical decisions.

Warmly, Cara, Diane, Blake and West Tarricone

We are open to speaking with any member of the committee. Please feel free to contact us with any questions you might have and we will do our best to answer. Thank you again!