

TESTIMONY OF HEATHER L. SHUKER
BEFORE THE PENNSYLVANIA SENATE
COMMITTEE ON LAW AND JUSTICE
ON SB 1182 THE GOVERNOR RAYMOND SHAFFER COMPASSIONATE
USE OF MEDICAL CANNABIS ACT

Good Morning Chairman McIlhinney and Ferlo and Members of the Committee:

My Name is Heather Shuker and I am from Butler County, Pennsylvania. I am submitting testimony to urge the Committee to pass the Governor Raymond Shaffer Compassionate Use of Medical Cannabis Act.

I'm a Mom to Hannah Pallas, a 10 year little girl who suffers from intractable epilepsy and epileptic encephalopathy consistent with Lennox Gastaut Syndrome. Her clinical diagnosis is currently unknown. Hannah is quickly declining. She has failed to have adequate seizure control on over 18 different seizure medications, the Ketogenic Diet, the Gluten Free Diet, the Vagal Nerve Stimulator and IVIG blood transfusion treatment. She still has atleast 100 seizures a week. Many times the seizures have been as high as 300 a day. Many of her seizures are subclinical in which we cannot physically see. We administer emergency medication atleast weekly. Hannah is developmentally delayed and non-verbal. She no longer smiles, laughs, feeds herself, or enjoys life due to the side effects from the anti-epileptic medications she is taking along with the effects of the weekly use of emergency medications.

Side effects such as insomnia, dizziness, hallucinations, headaches, lack of coordination, uncontrollable movements, severe breathing problems and paresthesia. These medications have many more side effects; however, most times I do not know what she is feeling as she is unable to communicate to me.

My daughter is quickly diminishing away. I am pleading with you all that you vote yes to SB 1182 to save Hannah's life and others who suffer as she does. I encourage you to view a video I created that depicts how poor Hannah's quality of life has become. The video can be found by searching "Heather Shuker Intractable Epilepsy" on YouTube or by the following link: <http://www.youtube.com/watch?v=97uhkL5IVaw>.

Please view this video and imagine what you would do to save your child or grandchild. We do not have time to wait for FDA approval. This madness has to stop today. It is unacceptable to have one more child die because of ignorance. Please educate yourself and those around you that this is a substance that has medicinal healing qualities and it is saving lives!

Hannah and I love the state that we live in and are thankful for all of the services she receives as a special needs child. Services I fought hard for. Services that cost this state quite a bit of money. Could you imagine the cost savings Pennsylvania would have if medical marijuana were legalized? Decreased ICU stays, costly medications and hours and hours of in-home nursing care to name a few! It is incomprehensible that we will have to move to have access to this plant. It is not right and is unacceptable.

Hannah's neurologist, Dr. Shelley Williams from the Children's Hospital of Pittsburgh and her Primary Care Physician of 10 years, Dr. Lydia Comini-Turzai are both in favor of the administration of medical marijuana for Hannah. Both physicians have written letters of recommendation.

Access to medical marijuana should be left to the responsibility of Hannah's physician's, not the government. I am able to administer Versed, an emergency medication at home that can cause severe breathing problems. This medication should be used only in a hospital or medical office under the care of a health professional according to the medication guidelines. In fact physicians will only prescribe this at Children's Hospital of Pittsburgh if a child is in the ICU. So why is a physician able to prescribe this for in-home use and I am able to administer it at home? We also have had Hannah on a Non-FDA approved medication for years from another country that her neurologist was able to write a prescription for. How was this exception made?

Time is of the essence. We cannot afford to have another child die in Pennsylvania because of unjust laws.

Bottom line is that my daughter needs this oil now as do many other children. Some children are not to the point of neurological deterioration that Hannah is at ... but why should they have to get to that point? Please stop this insanity and help these children now.

We are running out of time. We need SB 1182 to pass now! Our children should not have to die because we are waiting on the federal government to legalize before our state.

Thank you for your time and your prompt attention to this time sensitive mission -

Heather L. Shuker
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