

TESTIMONY OF CARA SALEMME  
BEFORE THE PENNSYLVANIA SENATE  
COMMITTEE ON LAW AND JUSTICE  
ON SB 1182 THE GOVERNOR RAYMOND SHAFFER COMPASSIONATE  
USE OF MEDICAL CANNABIS ACT

My name is Cara Salemme, my husband Chris and I reside in York County with our three beautiful sons, thank you in advance for taking a minute to read our testimony.

Jackson was a bright, beautiful, amazingly funny little boy until a week after his fifth birthday (he celebrated with his twin brother Parker). Jack got a virus, it went to his brain and he is very lucky to be alive. I credit his survival to prayer and to the amazing doctors and nurses at PennState Hershey Medical Center. He is now left with intractable pediatric epilepsy; he hasn't spoken in almost 3 years, functions currently on a nine to eighteen month age level, seizes daily and has a locked cabinet full of toxic medications that do not work.

While you are waiting for more evidence and FDA approvals and all the other organizations that we as parents are hearing need to be on board before we will be taken seriously, I assure you that the potentially deadly seizures our children are suffering from won't wait. Seizures don't wait for my child to be at home tucked into his bed hooked up to his oxygen monitor, seizures don't wait for him to be up the stairs before striking, they don't wait for his brother's soccer game to be over. Feeling completely out of control of our child's life we research...relentlessly. We read studies, I am mistaken daily for a nurse because I know all of the "lingo". I can decipher the language in a Pub Med article as well as I can read Dr Suess. We brainstorm with Jacksons neurologist and CRNP and dietician monthly, we joined support groups and talk to other parents daily, we keep Jack as safe as we can while weighing the benefit verses risk of brain surgery and diets and yet another medication with a laundry list of side effects. We enjoy every second we have with him and we say I love you a million times even though he can't say it back.

I am not looking to educate you on CBD oil, or its non-psychoactive properties, the 85% of children with intractable epilepsy that are seeing a 50-100% reduction in seizures or the science behind that, someone else has already done that and I have a feeling your mind is already made up in that regard. Today I am asking you to put yourself in our shoes... picture your happy healthy firstborn at five years old, seizing, turning blue, unable to speak, every seizure causing brain damage, every medication a gamble, your options are dwindling your child is fading right before your eyes and you KNOW that at one of your appointments soon the neurologist is going to tell you there is nothing left. That answer is unacceptable. There is something else... a last resort option that has the potential to change lives (as it already has for a number of children that were lucky enough to live in the right zip code.) I cannot let that go...you would not let it go either. Please support SB1182, for Jack... for Hannah and Anna and Cameron and the hundreds of other children across Pennsylvania that could benefit from this treatment. Support SB1182 for YOUR child and grandchild, our group is thinking of them already, no child left behind. No parent should have to move mountains (or move to the mountains) to obtain a promising medical treatment. By supporting this bill you are assuring future generations will have a medicine readily available for a disease that doesn't have time to wait for the politics to catch up.

In closing I would like to say I fully believe that current medications have a place in the treatment of any disease, epilepsy included. In this case, Jackson did not "fail" the medications...the current medications available failed him. Modern medicine has failed him, and it is time to try a different approach. I won't give up on him, ever.

Respectfully,  
Cara M. Salemme  
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