

TESTIMONY OF DEENA L. KENNEY
BEFORE THE PENNSYLVANIA SENATE COMMITTEE
ON LAW AND JUSTICE
ON SB1182 THE GOVERNOR SHAFFER COMPASSIONATE
USE OF MEDICAL CANNABIS ACT

Good morning Chairman McIlhinney and Ferlo and members of the committee. My name is Deena Kenney and I am from Lehigh County , PA. I am submitting this testimony to urge the committee to pass the Governor Shaffer Compassionate Use of Medical Cannabis Act.

I am here today to share my son Christopher's story and discuss how medical cannabis could potentially help my son and others with intractable epilepsy.

Chris is 17 years old and suffers from a rare genetic disorder called tuberous sclerosis. This disease causes tumors to grow in any organ of his body . It also causes parts of the brain to harden. Because of this hardening, in it's more severe manifestation, it can cause uncontrollable seizures, autism, mental retardation and behavioral problems. My son has all of the above. At the time of his diagnosis, his neurologist told us we were looking at many medication changes and possible brain surgery in the near future all in an effort to control the seizures. She said to me " Mrs. Kenney, you are about to find out why we call what we do a "practice" because that is exactly what we are doing a lot of the time". I had no idea how true her words would prove to be.

Christopher started having seizures at 6 weeks old. They started fast and furious, quickly escalating to 80-100 a day for the first two years of his life. His seizures got so bad at one point, that he was temporarily paralyzed on the left side of his body from non stop seizure activity. Over the years we have tried everything in an effort to gain control of his epilepsy. To date, he has tried 17 different anti convulsant medications in numerous combinations, one experimental drug from another country, dietary changes and supplements , and two surgeries- the first was a brain surgery to remove ¼ of his right frontal lobe and the second, most recent, to implant a device called a vagus nerve stimulator. Despite all of this he has still had thousands of seizures over the years including 4 status seizures, two of which became life threatening and required a medically induced coma and life support. As you can see, most of what we have tried has failed either because it didn't offer seizure control , it increased his behavior, or the side effects were not tolerable. Some of the side effects he's experienced from these various medications have been horrible.

5 made him hyperactive.

2 made him unable to sleep

1 lowered his blood pressure

1 gave him mouth sores and immune suppression

6 made him agitated and aggressive.

2 caused psychosis

1 caused hallucinations.

1 gave him liver toxicity that required hospitalization

and

1 upended our lives for 5 months by causing violent rages..a common side effect listed for this medication.

These episodes were pure, vicious , laser focused rage. With this type of violence the rage is targeted toward one individual and that target was me. Chris would attack me with intent to kill me, pinning me on the floor punching and kicking me. When he couldn't get near me he would throw anything he could at my head. Once he threw a glass bowl that narrowly missed my head and shattered on the wall. My daughter screamed and cried because she thought it hit and killed me. After successfully breaking several items on my head I started to wear this helmet at all times in my home to protect myself. If it weren't for my amazing husband taking care of Chris while still protecting me, I might not be here today to tell my story. It took months to wean Chris off of this medication because every time we would decrease the dose, he would have rebound seizures where he would turn blue and stop breathing. Remember, all of this was due to a side effect of a legal FDA approved medication.

Medical cannabis first came to my attention in 2009 when I saw a woman on Good Morning America who used it for her 10 year old son with severe autism. It stopped his aggressive behavior so successfully that he avoided going into a residential treatment facility. How did he take this cannabis ? He ate it in a cookie. One cookie per day was all it took. I was amazed as I know how difficult it is to control the aggressive behaviors that often accompany autism. They are harder to control than seizures sometimes. Then this past August while facing the prospect of putting our son on a drug that has two FDA black box warnings on it, one because it can cause blindness and one because it can turn the skin blue, I saw the CNN documentary WEED by Sanjay Gupta and I saw the story of Charlotte Figi whose 300 weekly seizures were finally controlled by medical marijuana with no side effects. I also found out that she is not the only one who is successful. There are others.

As we have no other options left at this time, I would like the opportunity to try medical cannabis for my son's seizures but I can't because there are outdated laws that prevent me from doing so. Laws that were made before we had the scientific ability to effectively study this plant . Laws that say it is dangerous. I find these laws hypocritical especially since our own US government has a patent on certain cannabinoids in this plant saying they are, in fact, neuroprotective. As marijuana is ubiquitous in our society , it appears as though the laws have done little to stop it from getting into the wrong hands but rather prevents it from getting into the right ones! I don't know if cannabis will help my son, but I can say what it won't do. It won't damage his liver, it won't give him diabetes, it won't cause blindness or turn his skin blue, it won't cause him to beat me, it won't damage his heart or kidneys and it won't kill him. The same can not be said for his current medications or those we have tried in the past. I urge you to please reconsider your position regarding this potentially life saving treatment. Thank you!

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