

NAME: Carey Tilghman

HOME ADDRESS AND ZIP CODE: 20941 San Mar Road; Boonsboro, MD 21713

PHONE NUMBER: [301-693-2073](tel:301-693-2073)

Good Afternoon Senators of the Education Health and Environmental Affairs Committee,

I am writing to ask that you **SUPPORT SB 604**

You may remember Raina and I and her big sister Paisley when we testified on 3/2/2017 regarding delays in implementation of the Maryland Medical Cannabis program and patient access to medicine. Since my last testimony, Raina had her third life flight in the summer of 2017. This time it with the MD State Police in Trooper 3 from a field close to our home. That flight and admission are her most recent trips to stay in the hospital.

The reasonable right of my 4.5 year old daughter Raina being able to ride the bus, attend school and be present at school sponsored activities and events with access to and administration of her cannabis medicine as maintenance and rescue for tonic clonic seizures will greatly expand opportunities for our family.

The limits to number of registered caregivers and prohibition of medical cannabis from school grounds has significantly impacted our immediate and extended family.

The adjustment of caregiver restrictions for pediatric patients will ensure that, if something happens to me, Raina will have an additional registered caregiver who can purchase and transport her cannabis medicine. It would also allow for Grandma or Grandpa to become a registered caregiver to have all their grandchildren for an adventure day or weekend as long as they stay in Maryland.

We could not in good conscience accept any school based special education placement for 2019-2020 school year for Raina without access to the Diluted Full Extract Cannabis Oil, the oil that has kept her out of helicopters and the Emergency Room; we have not even called an ambulance since August of 2017. Due to prohibition of medical cannabis and CBD products on school grounds, we have not as a family been able to attend school events such as concerts and performances, science fair, trunk or treat, STEAM night. We cannot as a family attend high school sporting events and support our nieces and nephews. My 7year old son Finn is directly impacted. He wishes to participate in some athletic teams but he cannot because practices or games are held on school grounds and it is very likely his little sister will need to go along too. My husband and I could not both attend the IEP meeting for our 3rd grade daughter. I can't pick up or drop off a sibling at school with Raina and her first line rescue cannabis based medicine.

Raina is given a small amount (micro dose) of cannabis oil 4x a day for maintenance of

epilepsy and autism, if she has a life threatening tonic clonic (grand mal) seizure the oil is administered orally and topically at onset of event.

Since beginning first CBD at 7mo old in 2016 and dispensary cannabis products at 3y years old, she has only been administered her pharmaceutical rescue three times. When administered the pharmaceutical rescue Diastat (10mg Valium/43lb 4yo), transport to hospital is required to monitor airway and breathing. If administered, pharmaceutical rescue it takes her about 30 days to return to baseline skill set. The baseline skills she has lost directly related to pharmaceutical rescue include:

- 1- almost all mobility. Active toddler running jumping & climbing to neonate unable to roll, clear her chin. (Summer 2016 & Summer 2017)
- 2- her ability to swallow has been lost and we needed to use a feeding pump and nasal gastric tube for feedings.
- 3- Raina is a thumb sucker and lost the ability to self soothe and bring her hand to her mouth for a period of 6 weeks after pharmaceutical rescue.

The “side effects” of medical cannabis are known as entourage effect. Below are what we have observed and noted after switching from full spectrum hemp CBD to dispensary products modified (diluted) to allow for exact micro dosing of medical cannabis.

1- Raina plays with things, she knocks over things her brother builds, she clears table tops in a single sweep of the arm, she wants to help with dishes splashing in the sink and stealing the wash rag as often as she can. She rarely explored anything before the switch to medical cannabis; she’s now playing with toys. She is manipulating objects boxes, coffee cans, her cups, books, etc. This inquisitiveness in objects is new: Flip the box, sit on the box, sit in the box, put the box on her head!! All amazing developmental progressions that we were not sure we would ever see.

2- She is sad when she falls. She has emotional reactions to her environment and things that happen to her.

3- Significant increase in verbal communication abilities including increase in range of tones and letter combinations and inflection. Within the last month she has said ma not in reference to me as Mom but she has the mmmaaaa letter combination. (I believe someday she will say it for real)

4- She brings us her cup communicating her needs. She shows joy and excitement as we shake her formula package jumping in anticipation.

5- She is beginning to hold hands and walk with someone. We continue to work on the stop direction but walking and holding hands is huge. She is not just collapsing or pulling the other direction. She is safer when navigating.

6- Our dog Penny is not just a mountain of fluff that Raina climbs over, she now seeks comfort in the soft dog and pets her. On walks Raina has realized that there are other things that make similar noises to our dog Penny. She looks intently between the two dogs.

7- She has learned to chew. She is picking up and exploring food and non food items orally. A developmental milestone.

8- Raina has opinions she is sharing with anyone that will listen.

Access to and administration of her cannabis medicine while in transport on the bus & educational settings is completely reasonable. Expanded caregiver numbers are not only needed for pediatric patients like Raina but for vulnerable adults who may not be able to purchase their own medications.

SB 604 will have a tremendously positive impact on our family. Medical cannabis has had a profound entourage effect on my child's cognitive development and she deserves to expand these cognitive capabilities in school with direct access and administration of medical cannabis maintenance and rescue. Furthermore, as a pediatric caregiver, I should be permitted to carry and administer medical cannabis to preserve the quantity and quality of my vulnerable child's life.

Thank You,

Carey Tilghman