

SUPPORT HB617

Name: Stephanie Flamino Pippen

Address: 514 Silverbark Court, Millersville, MD 21108

Phone: 410-320-4450

Good Day Delegates-

Thank so much you for your time and consideration of HB0617

My name is Stephanie Flamino Pippen. I live at 514 Silverbark Court Millersville, Maryland 21108, with my husband, Jason, and our two children Maxwell and Mimi.

Our son Max is 19 and our daughter Mimi is 15 years old. Both of our children are developmentally delayed with comorbidities, that include Uncontrolled Epilepsy. Max and Mimi receive Special Education services through AACPS Home and Hospital Teaching Office.

Max was born with a then unknown disability. He was diagnosed with epilepsy while he was in AACPS Infants & Toddlers Program. It was then, 16 years ago, that Max started the beginning of a very long list of anti-epilepsy drugs, or AED's.

All AED's have side effects. For the very lucky, some is actual seizure control, but AED's may cause seizures, as well. Some AED'S are so horrible that they cause rage and aggression, which then requires an additional prescription of an anti-psychotic medicine.

Max has been treated with drugs that make him angry, sleepy, hyper, aggressive, Obsessive-Compulsive, flat affect, anorexic, self-injurious, aspiration pneumonia, rashes, tremors, erratic cardiac rhythms, and can compound his cognitive impairments, just to name a few. Also, many AED's haven't been approved for children under 18. But his worst side effect was in 2015, when Max's bones started breaking as he was walking. My son at 19 has osteoporosis from AED's.

When Max was three, we were told that the best thing we could do for him was for us to have another child, so he could grow and learn through his sibling. His sister Mimi was born with the exact same genetic condition. At her birth, we were able to see that both children shared the same partial trisomy. As stated, Mimi also

shared Uncontrolled Epilepsy. Unfortunately, at age five, a car accident changed Mimi's epilepsy to a very rare progressive epilepsy called Lennox Gastaut Syndrome. This severe form of Epilepsy is just devastating. AED's are piled on top of one another, and other drugs are added or weaned to control the AED side effects. Mimi had lost her eyesight, her ability to eat, to walk, and she has dystonia and is in a wheelchair. Mimi suffers COPD and Asthma – all of these are side effects of AED's, or the additional drugs to control the effects of the accident.

EVERY day we are thankful that our children wake up. Our community calls our kids warriors, as they fight their illnesses daily and suffer the medicines they have been prescribed. They fight the seizures, they fight the pain, they fight their emotional, mental and physical losses every day. They fight the ability to join life in their own communities. They fight to live.

In 2014, Mimi lobbied for cannabis in Maryland, and we all won. While we waited for Maryland's first dispensary, we started hemp oil from Colorado. In 2015, Mimi's eyesight slowly returned. Mimi now uses glasses. In 2016, Max was able to remove all AED's from his system and for over two years he gained weight AND grew bones again. Better yet, Max started to read and use his communication device. Mimi uses an eye gaze device to show us her sassy side, too.

With Maryland cannabis, our children are on one AED. Cannabis controls pain, weight issues, eyesight, dystonia, asthma, sleep, & behavior, to name a few. Cannabis is a seizure RESCUE. Normally Epileptics use Benzodiazepines as a rescue to their seizure emergencies. Benzo's as they are called are used to calm the brain and nerves. Benzo's are addicting and have serious side effects, such as respiratory distress and death. And surprisingly they can even cause more seizures. Max and Mimi have not used a Benzo to rescue them from emergency seizures in months. Normally Mimi would use Benzo's several times a week, and Max every several months.

With Cannabis, our children are survivors. Mimi was normally admitted into the ER several times a year. Since our dispensaries have opened, we haven't visited the ER in almost two years! Cannabis saves our health care system.

We wonder what our lives would have been like if we had access to Cannabis sooner.

The trauma our lives would not have been endured. The healing we could have experienced, the many impairments we might not have suffered, the enjoyment of our school community. Your support of HB617 gives us hope for others.

Honorable Delegates, we ask you to please Rescue Raina and her Most Vulnerable classmates. Long-lasting repetitive events like epilepsy emergencies can prevent engagement, but the proper treatment of the events can create less trauma. And, the severity of our diseases with the clusters and intensities of events are less destructive and with fewer consequences long-term, too.

Cannabis allows us to survive. Cannabis allows us to live.

Please SUPPORT HB617. Please let students have access to their medicine or have the choice to access this medicine during school events, and on the bus.

Finally, we ask that we increase caregivers for both minors like Mimi, and adults like Max – or for Hospice patients like my mom. As a caregiver I cannot be everywhere, in fact, I should not be here.

I thank you for your time and thoughtful consideration of our requests.

We ask that you SUPPORT HB617

Kindest regards,

Stephanie F. Pippen

514 Silverbark Court

Millersville, Maryland 21108

410-320-4450