Jazmyne Hendricks

HB 1161 testimony

March 10, 2023

January 21, 2015 and September 2, 2016 are two days that have changed my entire life completely. Since then, there have been huge burdens and inconveniences placed on my life. Not only has this affected me since 2015, but it will continue to do so for the rest of my life.

On the day of January 21<sup>st</sup>, 2015, my mother took me to my yearly pediatric appointment. Dr. Parrish explained the importance of why girls my age need the HPV vaccination shot. Although I wasn't comfortable taking it, she convinced my mother that it was the best option for me. I received the Gardasil HPV shot that day. On September 2, 2016, I received another dosage of the HPV vaccination shot. Since then, I would wake up every morning and spill my cereal, drop/break dishes, trip up and down the steps, or fall on the floor. At times, I would go to school with big bruises on my legs because I kept falling in the shower. I thought that this was normal because it happened every single day.

My parents took me to the neurologist due to the mass amounts of headaches I would experience weekly. Fortunately, the doctor that was interning overheard the conversation about what I was experiencing in the morning, and she recommended that I have a brain scan done immediately. I received my test results stating I had *Juvenile Myoclonic Epilepsy (JME)*. My first, full-on seizure presented itself soon after early in the morning. Unfortunately, I've had several seizures as time progressed. The jerks have continued to be a part of my everyday routine.

As a person who lives and deals with JME every day, this is how it makes me feel/affects me:

- Feeling very dependent on everyone around me
- Has to be on other people's schedule so that they can take me where I need to go
- Relying on my friends to pick me up to go places
- Online university rather than on campus
- Paying for Uber every day for work
- Wasn't able to drive at 16 years old
- Having to deal with potential long-term effects of Lamictal (osteoporosis, osteopenia, memory issues)
- Not having a social life, can't drive to college campus/events
- Has to start my day around 1-3 pm when my jerks stop
- \$30 co-pay every month for medicine
- Memory loss
- Short-term memory issues
- Hard time focusing and paying attention/ makes work and school difficult
- Can't drink alcohol when I go out with my friends

- Can't stay up late (The later I stay up, the more jerks I have in the morning; Mentally it's harder to function properly)
- Random bruises on my body
- Puts stress on my parents for my well-being when I'm alone

If I could go back in time, I would have walked out of the doctor's office immediately. It has done nothing but find ways to disturb my life and the decisions I make. Years later, I am still embarrassed about the illness. Each day I try to find "cures" to make my life more normal again. Every day I still have hopes that I will simply "grow out of it" so that I can finally pick up where I left off the day before January 15, 2015.

Informed consent should be mandatory. I urge the Chair and Committee Members to vote in favor of HB 1161.

Sincerely,

Jazmyne Hendricks