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Delegate Alfred C.
Carr, Jr.

House Office Building, Room
222

6 Bladen St., Annapolis, MD
21401

February 5,
2020

Dear the Honorable Delegate Alfred
Carr,

I would like to voice my support for HB447, "Health Insurance – Pediatric Autoimmune Neuropsychiatric Disorders – Coverage." My oldest son, Henry, age 7, was diagnosed with pediatric autoimmune neuropsychiatric disorder (PANDAS), a neurological condition that is caused by common streptococcus bacteria that travels beyond the blood-brain barrier and causes encephalitis (swelling of the brain) leading to a behavioral response. As a parent of a child diagnosed with PANDAS, it has been frustrating the limitations in resources and available insurance covered treatment options. This condition and the limited available treatments have caused my family economic and psychological / emotional hardship.

My wife and I have spent, tens of thousands of dollars out of our own pocket beyond what is covered by insurance, over the past several years, on medication (a cocktail of prophylactic antibiotics, stimulants for treating ADHD symptoms, medications to balance the effects of the stimulants, and anti-inflammatory medication) and behavioral, neurological, and medical specialists for Henry. The condition, during a flare causes Henry to have neurological ticks, an eating disorder, rage, a lack of understanding, a general disregard for rules, and a combative personality, which he generally does not possess otherwise. According to Henry's neurologist who specializes in PANDAS, we have exhausted most therapies for his condition. His neurologist is recommending a therapy, IVIG, which has been shown to be promising for

children with his condition. Henry's neurologist has submitted on several occasions for pre-authorization from Blue Cross and Blue Shield, our health insurer, for IVIG therapy, which has been consistently denied. The cost, out of pocket, for this therapy is between \$16k and \$20k per infusion and it is not uncommon that children with PANDAS will require several infusions.

While Henry is not receiving the care that his physicians are recommending due to insurance denials, his behavior during flares (times of brain swelling) causes psychological and emotional harm to himself and the other individuals in his household. It is not uncommon that Henry inflicts physical harm to his brothers, including a recent incident where he hit his 5-year-old brother in the eye with an object, which led to an emergency room visit. His 5-year-old brother no longer wants to sleep in the same room as Henry and has been to therapy for issues we believe are based on his exposure to his older brother during flares. Henry will scream at all family members if he does not get his way often for hours. Our 2 year old has started imitating Henry by screaming through dinner every night.

I am afraid of the long term consequences for children with his condition, since if and when it worsens or is left untreated since encephalitis can cause major brain damage which will burden the child for the rest of their lives, potentially costing the individual afflicted, the families, and society a staggering amount of money, time, and resources.

This bill, when signed into law, will allow better resources and available treatments here in Maryland.

Thank
you,

Matthew
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