26 February 2020

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Individual Written Testimony in Support of Bill SB475

AN ACT concerning Health Insurance –

Pediatric Autoimmune Neuropsychiatric Disorders – Coverage

Sponsors: Senators Sydnor, Kelley, Waldstreicher, and Zucker

Good afternoon. I'd like to thank Senator Sydnor, Kelley, Waldstreicher, and Zucker for sponsoring this bill, Senate Bill 475. I support this bill and I'm hoping to see favorably reviewed and ultimately passed.

My son Alex couldn't be here today to tell you his story personally, but that's a good thing. He's in school. He's a senior at Centennial High in Howard County. He'll be graduating in May. That's a big deal for any family, but it's an even bigger deal for ours. It's taken all of our strength and considerable personal resources to get him there.

His PANDAS started in August 2010, just before entering 3rd grade. Since then, his insurance covered treatments have included antibiotics, antianxiety medication, steroids, a tonsillectomy, cognitive behavioral therapy, but what has proven most effective in keeping him functioning and in school has been IVIG. Unfortunately, he didn't undergo his first IVIG treatment until April 2014 (7th grade). We had to put it off because of the cost, $10,000, which our provider, Blue Cross/Blue Shield, would not cover. So, my mother-in-law helped us out.

We're a single income household. Managing the symptoms of children with PANDAS or PANS and keeping them in school is a full-time 24/7 job that fell primarily on my wife. It was very difficult keeping him in school because his OCD was so bad. He missed three-and-a-half consecutive weeks of the 7th grade before his IVIG. It took a few months afterwards, but he improved.

In 2018 (11th grade) he somehow contracted Bartonella's disease, a bacterial disease transmitted by fleas or cats, sometimes known as "cat scratch fever." This time, his autoimmune response affected his appetite and the part of his brain that makes you feel satiated. He would try to eat and then throw up. At 17 years old, he was 6'2" and his weight dropped to 133lbs. This time, because he had grown so much and needed more immunoglobin, the IVIG treatment would be double what it was the first time ($20,000). So, this time I had to

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take out a personal loan. Now he's seeing a Bartonella's specialist in addition to his neurologist, Dr. Elizabeth Latimer.

It's taken a lot of effort, not just for Alex, but for his younger sister, his mother and myself, and considerable expense to keep him in school. We're fortunate to have been able to pay out of pocket for his treatments. However, if our insurance would have covered IVIG, he would have been able to get it sooner and wouldn't have had to struggle as much through his classes. We wouldn't have had to put it off as long as we did in both instances. We tried everything else to manage his symptoms, but were only delaying the one that has been most effective because it was not covered by our insurance.

Not all families are able to pull together the resources to pay ten or twenty thousand dollars for treatments their insurance companies won't cover, and this has dissuaded more than one family we've encountered from seeking out PANDAs specialists like Dr. Latimer. I've been told that our insurance would likely cover Rituximab, another treatment his doctor said would be as beneficial as IVIG, once he turned 18. That's little comfort to 8-year-olds who have to make it through grade school to graduation or to their families. These kids will never be able to "do over" their elementary through high school education and live normal childhoods. This is the challenge we and our children face.

Thank you for your time.