

[REDACTED]

Feb. 28, 2019

To Whom It May Concern:

This letter describes, briefly, our challenges in securing insurance coverage for our daughter [REDACTED] treatment of PANDAS with intravenous immunoglobulin (IVIG). [REDACTED] was diagnosed with PANDAS several years ago by Dr. Elizabeth Latimer. While Dr. Latimer was an out-of-network physician with our insurance, we were able to secure coverage for office visits using our insurance's gap exception provision. After a year and a half of treatment, Dr. Latimer recommended IVIG therapy for [REDACTED] based on her laboratory test results and the success of immunomodulatory treatments with oral steroids.

We completed this IVIG treatment at Dr. Latimer's office, incurring out of pocket costs in excess of \$13,000. In order to pay for this, we drained savings and tapped a retirement account. After hearing the stories of many other PANDAS families who were in worse financial position after years of fighting for treatment, my husband and I found ourselves grateful that we were in the position of having a retirement account to use.

After the treatment, our daughter improved significantly. Over the next year, she doubled her reading level and was exited from special education. At the same time, we spent that year fighting with our insurer for reimbursement, ultimately unsuccessfully. We appealed through all channels available to me as a state-insured Maryland employee. We went through peer review and a final appeal, all of which were denied on the grounds that IVIG was "experimental", while watching our daughter improve by leaps and bounds before our eyes. Our appeal was ultimately denied because the reviewer found we had not presented "laboratory confirmation" of PANDAS, despite the fact that no FDA-approved "test for PANDAS" exists and PANDAS is ultimately a clinical diagnosis. This entire process consumed approximately 80 hours on my part, between speaking on the phone to insurers, assembling materials for various levels of appeal, and researching and writing responses to denials.

Seeing the improvement in our daughter, we would go through all of this, and more, again in a heartbeat. However, we are also painfully aware that we were among the lucky ones: we had savings and retirement to tap, and our daughter improved after one treatment. For families with fewer financial resources, or families needing multiple rounds of therapy, HB 15 would rectify a glaring inequity and enable their children to function again. Please support this bill as an avenue to provide critically necessary care to severely ill children. Thank you for your consideration,

[REDACTED]

PANDAS parent

[REDACTED]