

Monday, February 16, 2020

Dear Representative Linehan, Senator Moore, and Members of the Committee On Children,

I am writing in support, if there are specific changes, to Raised Bill 5144: An Act Requiring Health Insurance Coverage For Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections and Pediatric Acute-Onset Neuropsychiatric Syndrome. The passage of this bill, with appropriate changes, will positively impact children and their families suffering from Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS).

The PANS/PANDAS community sincerely needs insurance coverage; however, Section (b)*1 must be removed from the bill. Otherwise, Bill 5144 is not supportable and should not be passed. First, there are zero FDA approved treatments for PANS/PANDAS. FDA approval is tough to get, and the process is slow. Nine diseases have FDA approval for IVIG, but over 200 disorders are using IVIG successfully off label. Second, this section of the bill puts PANS/PANDAS patients at a significant risk of losing coverage for current and future treatments. Unfortunately, we have seen insurers use language within a PANS/PANDAS patient's file to deny coverage for being diagnosed with PANS/PANDAS or merely having the cluster of symptoms that align with a diagnosis. For example, if a PANS/PANDAS patient has been prescribed IVIG, and it is covered under Primary Immunodeficiency, this bill allows insurers to deny IVIG because the patient also has PANS/PANDAS. This would be a devastating and possibly life-threatening denial. Even if the doctor can change that denial through a lengthy peer-to-peer review, valuable treatment time will be lost. This scenario could happen with any treatment recommended for PANS/PANDAS. Therefore, I cannot support this bill with this language in it.

I am linking to a PANS/PANDAS insurance bill from Maryland. I would fully support the language of this bill. *2 Please read it for your consideration when editing this current bill.

I would like to take these few moments to emphasize the critical nature of this bill to those constituents in your districts who will directly benefit from its passing. PANDAS/PANS/AE are debilitating in all aspects to a child's life, their parents emotional and financial well being and the school system in which they attend. Inappropriate and ineffective treatments that do not address the medical condition cost the insurance companies and the state of Connecticut and do not help heal the child. A short overview of causation is that it is a rogue immune system response to an illness such as strep throat or other infection that causes the body to make antibodies attacking the brain in these children. This attack causes brain inflammation and can result in seizures, psychosis, tics, OCD, food restriction to name just a few. For us personally, our daughter presented with nearly every possible symptom.

Delaying advanced treatment results in continued brain inflammation that requires longer and more expensive treatment protocols. We are doing both the state and the very insurance companies that may oppose this bill a service in requiring coverage for the treatments ordered by these children's physicians according to published standards of care. With prompt and appropriate treatment these children can recover and live a productive and normal life; without appropriate treatment they can potentially be debilitated and reliant on state and federal services for their entire life. The cost to the state for a constituent on lifelong disability is a cost we would like to avoid.

Treatments required for severe cases are may include IVIG, high dose IV steroids and Rituxan (an immunosuppressant). IVIG helps by introducing healthy antibodies into the system to retrain children's immune system to function properly.

The number of children with pans / pandas can be as high as 1 in 200 however only very severe cases require these more invasive interventions.

By passing this legislation you allow us to restore our children and return them to the greatest potential they were born to fulfill.

Please remove section b of Raised Bill 5144: An Act Requiring Health Insurance Coverage For Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections and Pediatric Acute-Onset Neuropsychiatric Syndrome and use the Maryland bill language as your guide and I will support the bill and urge your support too.

Best regards,

Anita Serpa-Smith

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*1 (b) Each individual health insurance policy providing coverage of the 11type specified in subdivisions (1), (2), (4), (11), (12) and (16) of section 1238a-469 of the general statutes delivered, issued for delivery, renewed, amended or continued in this state on or after January 1, 2021, shall provide coverage for outpatient prescription drugs approved by the federal Food and Drug Administration for treatment of pediatric neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome.

*2 Maryland SB 475

MD SB 475 Information: <https://legiscan.com/MD/text/SB475/2020>