

1/28/2020

Alena Whitt  
10330 W. Hyatt Rd.  
Ijamsville, MD 21754

Dear Representative,

I am writing to inform you of current health insurance industry policies that prevent treatment for autoimmune disorders that two of my three children suffer from.

In 2012 my daughter was diagnosed with PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus). And in 2013 my son was diagnosed with PANS (Pediatric Acute onset Neuropsychiatric Syndrome). PANDAS and PANS should be recognized by the medical community and health insurance industry as forms of Autoimmune Encephalitis. Clinically, both of these conditions present with numerous neuropsychiatric symptoms that mimic other recognized types of AE. These disorders are autoimmune mediated. In simplest terms, the body produces antibodies to attack an actual or suspected infection. However, in children who have PANDAS/PANS their antibodies breach the blood-brain barrier and attack healthy tissue in the brain (the basal ganglia) and that causes severe neuropsychiatric symptoms ranging from anorexia, OCD, anxiety, rage, emotional lability, age regression, separation anxiety, mutism and more. Unfortunately, many physicians are not educated on how to properly diagnose and treat these disorders. Due to lack of prompt medical care as a result of PANDAS/PANS not formally acknowledged by the medical community, my daughter missed the majority of 4<sup>th</sup> grade, and my son suffered an acquired brain injury rendering him mute for over a year. In 2015 my daughter was also diagnosed with Autoimmune Dysautonomia. In 2017, our son was diagnosed with CVID (Common Variable Immune Deficiency or primary immune deficiency) and our daughter was diagnosed with Autoimmune Autonomic Neuropathy and CIDP (Chronic Inflammatory Demyelinating

Polyneuropathy). Today, with their current diagnoses, my children, now 18 and 20 years old are able to receive IVIG treatment through insurance coverage. However, I will always question whether or not my children's current autoimmune conditions could have been prevented had they received a prompt diagnosis and the recommended treatment protocol for Autoimmune Encephalitis when they were initially diagnosed with PANDAS/PANS.

The challenges parents face with PANDAS/PANS can be insurmountable. Since my children's first diagnosis we have sought effective medical attention, proper diagnosis and effective treatment. However, we encountered uneducated physicians, near personal bankruptcy and insurance industry obstacles each step of the way:

1) Inadequate awareness by physicians and insurers of these disorders. We have taken our children to more than 30 physicians in a 5 year time span to obtain medical care and a proper treatment plan. Aside from the time, energy and finances this took away from our family, my children lost this time. This is was part of their childhood that my children will never get back. As I researched, and networked and negotiated with physicians, insurance providers and school systems my children suffered.

2) There is an undo financial hardship placed on families with PANDAS/PANS children. PANDAS/PANS specialist physicians who can properly treat our children do not participate with any health insurance companies. This is because the treatments they prescribe are considered "off label" and these physicians, if they participated with a health insurance company, would be "red flagged" for prescribing treatments for a disorder that essentially does not exist to the health insurance industry. In 2012 and 2013 we were forced to pay out of pocket for the needed IVIG treatment (\$6,000 and almost \$10,000, respectively). Both children had a clear improvement in symptoms after they received just one treatment, however, we were not able to continue treatment and their health declined shortly after

receiving IVIG. In 2016 we paid \$14,000 out of pocket for our daughter to receive a second treatment in an attempt to abate her failing health.

3) The treatment we obtained was high dose IVIG, or Intravenous Immunoglobulin. This is the typical treatment protocol for Autoimmune Encephalitis and other autoimmune related conditions. However, mainstream doctors and most health insurance companies do not accept PANDAS/PANS as a form of Autoimmune Encephalitis and do not cover the treatment expenses. The cost of each infusion depends on the weight of the child. IVIG treatment is based on the patient's weight and it costs roughly \$1000 per every 10 lbs. that a child weighs. This means that if a child weighs 100 lbs. one IVIG treatment would cost roughly \$10,000, not including the office expenses and nursing care needed for a two day infusion. Most children need more than one IVIG treatment with these disorders. Our insurance company like many other national health insurance companies excludes coverage of IVIG for PANDAS/PANS and do not accept the disorders as a form of Autoimmune Encephalitis.

4) Almost every medical website, as well as Children's National Medical Center, The Children's Heart Institute, The Mayo Clinic, and the National Institutes of Mental Health state that IVIG is known to be effective for treating PANDAS/PANS, Dysautonomia and Autoimmune Neuropathy, yet health insurance companies deny the treatment that can actually improve a patient's quality of life and functionality.

5) We were told by two cardiologists and two immunologists that our children would likely benefit from IVIG, however none of those four physicians who participated with our health insurance would prescribe IVIG because they were constrained by the insurer and the inevitable denial of coverage they would issue. The insurance companies should not dictate to the physicians which treatments are acceptable and covered for patients. The potential insurer backlash and red tape to win approval for coverage are almost insurmountable obstacles unless parents can pay the full cost out-of-pocket.

I will never know if early, and continued, IVIG treatment would have prevented my children's illnesses from progressing into the debilitating conditions they suffer from today. However, I feel it would have. I

firmly believe that something must be done about the economics of our health care system. I am hoping that federal policies affecting the insurance industry relating to PANDAS/PANS can be changed. Our children deserve prompt and effective treatment for these disorders. The insurance industry should not be making treatment decisions for patients. My children suffered for 8 years, and there are thousands of others like them in this country who endure the same conditions. It is estimated that 1 in every 200 children suffers from PANDAS/PANS to one extent or another, and roughly 1 million to 3 million people suffer from Autoimmune Dysautonomia. Perhaps Maryland's insurance commissioner can prevail on the industry to take a more flexible position and acknowledge that IVIG is a legitimate treatment for PANDAS/PANS and many other autoimmune mediated conditions.

I would be pleased to provide you with additional information about our specific predicament and about Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus and Autoimmune Autonomic Neuropathy and Autoimmune Dysautonomia.

Sincerely,

Alena Whitt