

Testimony of Tara Richardson, M.D.
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Dear Chairman and Members of the House Insurance Committee,

I appreciate you taking the time to learn about PANS and working to ensure patients in Kansas have access to the optimal medical treatment.

PANS stands for Pediatric Acute-Onset Neuropsychiatric Syndrome. PANDAS is considered a subtype of PANS, and stands for Pediatric Autoimmune Neuropsychiatric Disorder associated with Streptococcal infections. PANS is a medical disorder with both physical and psychiatric presentations. Symptoms are caused by a misdirected immune responses that result in acute onset of OCD or restricted food intake, along with at least 2 neuropsychiatric symptoms in 7 categories. PANS is considered a diagnosis of exclusion, meaning the patient should be fully worked up for other known illnesses or diseases that could cause the observed symptoms. The workup should rule those other illnesses in or out. There is no age restriction for a PANS diagnosis. There is no lab test that can fully confirm or rule out a PANS diagnosis; it is based on observation of the cluster of symptoms by a medical provider. The true prevalence is unknown, due to poor diagnosis and awareness of the condition. Many children with PANS are diagnosed with a psychiatric illness and prescribed psychotropic medications rather than being evaluated and treated for an underlying infection. According to the PANS/PANDAS Consortium, the disorder affects as many as 1 in 200 children each year.

PANDAS was identified in 1998 by Dr. Susan Swedo of the National Institute of Mental Health (NIMH), when she identified a sudden-onset of OCD-like symptoms in children with streptococcal infection. PANS was described in 2010 as there were similar symptoms linked to other infectious or environmental triggers. It is believed that the body has a misdirected immune response and rather than attacking the source of infection, it affects host tissue resulting in brain inflammation. The basal ganglia is believed to be the affected region of the brain. The basal ganglia is a part of the brain involved in voluntary motor control, cognition and reward processes, executive functioning, behaviors and emotions. The same area is involved in tics and obsessive compulsive disorder.

65% of patients with PANS have a relapsing/remitting course. During each recurrence, symptoms can worsen, and new symptoms may manifest. In between flares, some symptoms may resolve completely but repeated flares can change baseline behavior. Treatment guidelines by the Journal of the American Academy of Child & Adolescent Psychiatry suggest a 3-pronged approach: antimicrobial treatment to remove the source of infection/inflammation, immunomodulatory treatment to decrease inflammation (this may include NSAIDs, steroids, and IVIG) and psychiatric treatment for symptom relief (this may include therapy and/or medication). Receiving timely and appropriate treatment is paramount to optimizing recovery.

My daughter Brielle developed PANS in 2019, when she was 5 years old after catching a common viral illness, rhinovirus-enterovirus. She developed many of the symptoms we have discussed, but most notably she developed a severe case of obsessive compulsive disorder, literally overnight. She believed she had swallowed various things like hair, worms and

eggshells, and that she was going to die. She would ask me hundreds of times daily for reassurance. She also believed food and water was contaminated and would kill her, so refused to eat and drink to the point of dehydration. She became uncharacteristically aggressive, and developed severe separation anxiety. She was symptomatic for approximately 6 months and was ultimately treated with antibiotics, anti-inflammatories and steroids. She had smaller, subsequent flares that were much more manageable as we came to better understand her symptoms. As a psychiatrist, I fully support the use of psychiatric medication if indicated but she never took any psychiatric medication. Today she is considered fully recovered, healthy, and doing well in school and extracurricular activities. I hope for the same for all affected children.

Respectfully,

Tara Richardson, M.D.

Historical information gathered from:

Swedo, Susan. "A Historical Perspective on PANS". Royal University Hospital in Saskatoon, Canada. 10 October 2015.

Zagor, F., and Kapetankais, C. (2020, June 20). PANDAS/PANS - The Frequently Misdiagnosed Behavioral/Neurological Syndrome. Retrieved December 10, 2020 from aspire.care/clinicians/natcon-behavioral-health-presentation/