

Summary of Segal Report

Dear Chairmen and Members of the House Insurance Committee,

I am Micaela Widman, mom of six in Overland Park. Two of my children had severe, debilitating, and life-threatening autoimmune encephalomyelitis, and thankfully are now at 99% remission.

Today I will be briefly summarizing the Kansas State Employees Health Care Commission Report on Insurance Coverage for the PANS and PANDAS Pilot. The 2022 House Bill 2110 required that the state employee health plan implement a pilot program providing coverage for diagnosis and prescribed treatment of PANS (pediatric acute-onset neuropsychiatric syndrome) and PANDAS (pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections). Coverage was subject to applicable deductibles, co-pays, and coinsurance requirements of the members, and coverage became available on January 1, 2023. The pilot program was ultimately established to help children suffering from PANS and PANDAS to get appropriate and much-needed medical care.

During plan year 2023, the state employee health plan had sixty-eight submitted claims for PANS and PANDAS. Twenty-six of these members incurred claims for PANS and forty-seven incurred claims for PANDAS. Some actually incurred claims for both PANS and PANDAS. Incurred claims for all members totaled \$82,159 in allowed charges and coinsurance of that amount. The state employee health plan paid \$75,386, with the balance paid by the members through deductible and/or coinsurance. According to the report, the estimated cost of coverage was less than 1/5 of a percent of the 2021 total projected plan cost, so the cost of coverage of PANS and PANDAS in the pilot program had minimal impact. However, the benefits to the patients and families were life saving and life changing.

Mason, Kai, Brielle, Asa, Luke and Alyson. You can't put a value on the lives and the quality of lives of these kids. I can personally share that before treatment, our son and daughter were debilitated. My son was only able to function a small fraction of the time, and my daughter was unable to function at all. Since treatment, my son has graduated from KU in computer science, is an avid disc-golf player, works out several times per week, has lots of friends, and has secured a career as a software engineer in North Kansas City. My daughter since treatment has become able to walk, speak, and eat again, and has regained her cognitive losses and many other abilities. She is a sophomore at Blue Valley Southwest – she plays the piano, she plays tennis, babysits, hangs with friends, and is striving to go to college to become a nurse or a nutritionist.

The state employee health plan has continued the pilot program coverage for PANS and PANDAS for pilot year 2024. If the benefit were to be expanded to all health plans in the state, members and more providers would become aware of the eligibility for this coverage for PANS and PANDAS, and it would be expected that more claims would then be incurred in future years.

This is a good thing because...left untreated, the costs of these illnesses are outrageously greater than if treated. The report says that early diagnosis and treatment are “ideal,” but better said, they are crucial. Early vs later intervention tremendously impacts the quality of life and prognosis of these pediatric patients, and proportionally, it also impacts the costs of the families and the state. When a child experiences an onset of a neuroimmune disorder such as PANS, PANDAS, or autoimmune encephalitis, at first, it is like a small, but significant fire that needs to be put out. It is scary, but it is fairly easily to control and overcome. However, if that child's neuroimmune illness is left untreated, it will grow and spread like a wildfire, affecting more body systems, affecting them more deeply, creating complexities that seem impossible to figure out and treat. The expenses can then become a massive burden to the families and the state. All to say, early diagnosis and treatment will *greatly* reduce the incidence of chronic and high-cost conditions which develop from untreated or delayed treatment of neuroimmune disorders such as PANS and PANDAS.

Thank you for letting us come speak with you today.