

March 10, 2022

Dear Mr. Chairman and Members of the Senate Insurance Committee,

Thank you for the opportunity to speak today regarding Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome. My name is Shannon Wright. This has been an over a decade long journey for me and my family. Over 10 years ago my daughter suddenly and without any known explanation at the time changed overnight on September 13th, 2011. This life changing event was traumatic for her and our family. It took 9 months of doctor appointments and research before she was able to finally receive the life saving treatment of Intravenous Immunoglobulin (IVIg) which brought her back to us. After she regained her health I became aware of a community of parents who had experienced the same tragic medical event in their own children. This group of parents started working together to bring awareness of PANDAS/PANS to Kansas. Many of these families testified or submitted a written record to the House Health and Human Services Committee along with treating physicians. We appreciate Governor Colyer for issuing the first PANDAS/PANS Awareness Day Proclamations on October 9, 2018. Representative Suzi Carlson has been a wonderful supporter. Governor Kelly has continued to issue proclamations in the following years. We are also grateful to her. Senator Brenda Dietrich provided an introduction to Representative Eplee who has championed our cause and authored the current bill you are considering today.

Our group has provided testimony in front of the Health and Human Services Committee two times. One day was before the legislative session started and included over 6 hours of testimony. We were then referred to the Insurance Committee. Testimony was given by two physicians to the Insurance Committee last year. In response to a request by the House Committee on Insurance a cost benefit analysis was ordered to research potential social and financial impacts of House Bill No. 2110. That report is now complete. I am here representing a group of parents who while spending a tremendous amount of resources to heal their own children also write letters, volunteer their time and money, support other parents with children beginning to show symptoms, not because they are going to personally gain from this bill being passed, but rather inspired to act because they do not want others to face the same pain and frustrations with the system that they have experienced. I am also here representing physicians who have cleared their patient schedules (some of them 3 times) in order to provide testimony in hopes of being able to help the patients that they treat. The individuals most impacted are the children. Today, you are going to have the opportunity to hear from Brielle and Mason who are courageously going to share their personal stories.

The PANDAS Network reports "PANS is when an infectious trigger, environmental factors and other possible triggers create a misdirected immune response resulting in inflammation on a child's brain. In turn, the child quickly begins to exhibit life changing symptoms such as OCD, severe restrictive eating, anxiety, tics, personality changes, declines in math and handwriting abilities, sensory sensitivities and more. PANS was first introduced in 2012 by Dr. Susan Swedo in the paper "From Research Subgroup to Clinical Syndrome: Modifying the PANDAS criteria to

Describe PANS” PANS is the overall umbrella which includes all possible triggers. PANDAS is under that umbrella, but only includes the strep trigger. The strep trigger was the first one identified when Dr. Swedo was conducting research on Sydenham Chorea (another strep triggered illness) in the 1990s.

Why does early and appropriate treatment matter? Because not only does PANDAS/PANS create a severe disruption in the life of a child and their family, but untreated (or treatment that is inadequate or has been significantly delayed) can cause permanent debilitation. IF treated early and in a timely fashion, PANDAS/PANS can remit entirely. IVIG is an important tool for physicians to be able to use if needed with their patients. Lack of insurance coverage makes the IVIG treatment inaccessible to families due to the high out of pocket costs.

Segal issued a report on November 22, 2021 to the State Employee Health Plan regarding House Bill No 2110- Coverage and prescribed treatment of PANS and PANDAS. The Segal report affirms the information already previously received through the testimony of parents and physicians to the House Health and Human Services and Insurance Committees. The report comes to the conclusion that not providing appropriate treatment would be more expensive for the State of Kansas than issuing an insurance mandate. “As illness progresses, what may have been treated in 1-2 sessions of PANDA treatments may now require hospitalization and/or residential care. Aside from not receiving proper treatment when needed, the long-term effects may extend into adulthood negatively impacting performance in school, on the job and in relationships...The survey results also revealed that at least 20% of patients with PANS and/or PANDAS experience a delay of more than 12 months before receiving appropriate treatment even after being diagnosed with this type of autoimmune encephalopathy.” Although I believe that the projected numbers may be inflated (for example not all children will require one IVIG treatment a year), Segal reported “the impact to claims cost and administrative expenses is expected to be minimal”

Using my own child and family as anecdotal evidence, we saved the State of Kansas thousands of dollars by paying out of pocket for IVIG treatment. While my daughter was very ill, her school wanted her placed on homebound services or in the most restrictive environment the district could offer. It was not an appropriate placement. To appease the school I asked for her to be assessed for the Severely Emotionally Disturbed waiver through the community mental health clinic in hopes of providing her more support at school. She qualified for the waiver and was issued a Medicaid card. My daughter received case management, attendant care and psychiatric services paid for by the State of Kansas. Meanwhile we had pursued the treatment of IVIG. We pursued IVIG after all other treatment options were exhausted. We paid \$12,000 plus travel expenses to Chicago for the treatment in April 2012. By the end of the summer she had recovered and was able to return to the general education classroom with special education support. Outside support was no longer needed. I discontinued the SED waiver and Medicaid card in September. I was curious and I asked the mental health clinic for a printout of all the charges to Medicaid over the spring and summer months. It equaled nearly \$10,000, almost the same cost we had paid for a treatment that actually helped her. If we had not pursued IVIG, the State of Kansas would have continued to pay for services that were not going to be able to assist her in her healing. I believe she would have ended up in a residential

treatment facility as this had already been recommended to us. Without the IVIG treatment the State of Kansas would have paid thousands and thousands of dollars. Providing IVIG coverage may actually save the State of Kansas money!

Representative Eplee has written a bill asking for a IVIG coverage pilot program for PANDAS/PANS in the State Employee Health Plan for the next two year. After two years and assessing the actual cost which I believe will be minimal, we would then like to extend coverage for IVIG throughout the State. I believe this bill will be cost effective for the State as well as providing needed relief for Kansas families and children.

Thank you for the opportunity to give my testimony.

Respectfully Submitted,
Shannon Wright
2513 SW Ancaster Rd
Topeka, KS 66614