



House Committee on Insurance

Written Only Opponent Testimony on House Bill 2824

Presented by William Wilk, Senior Director of Government Affairs

Wednesday, March 20, 2024

Mister Chair and members of the committee, my name is William Wilk, Senior Director of Government Affairs for the Kansas Chamber. The Kansas Chamber represents small, medium, and large-sized businesses across the state advocating for policies to improve the economic climate in Kansas. The Kansas Chamber appreciates the opportunity to submit opponent testimony on House Bill 2824, a bill mandating insurance coverage for pediatric acute-onset neuropsychiatric syndrome (PANS) and pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS).

Pediatric acute-onset neuropsychiatric syndrome (PANS) and pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) are inflammatory brain disorders that can become chronic or life-threatening conditions when left untreated. While these disorders are tragic others should not be collecting the costs for individuals with PANS and PANDAS. As of 2022, ten states have enacted similar legislation mandating insurance coverage for PANS and PANDAS disorders.

If a state decides to mandate certain disorders to be covered under insurance, it can impact insurance costs. If Kansas were to mandate the coverage of PANS and PANDAS insurers could spread the cost to all policyholders leading to increases in premiums.

According to the *National Institute of Health* it is estimated 1 in 200 children in the United States are affected by PANDAS or PANS. Rather than mandate coverage we encourage the legislature and proponent stakeholders to look at creating specialized insurance programs or appropriate funds specifically designed for the coverage of costs associated with PANS and PANDAS conditions.

The House Health and Human Services committee held a hearing on December 14, 2020, to learn more about patients suffering from PANS and PANDAS. I have attached the committee report to my testimony. The committee report does state there are no laboratory tests or biomarkers completely dependable for the diagnosis of PANS and PANDAS. Unfortunately, this is still true today in 2024.

Within that report conferees referenced their personal stories with PANS and PANDAS and the cost associated with treatment for these diseases. The report also mentioned Intravenous Immunoglobulin (IVIG) as a successful method of treatment for individuals suffering from PANS and PANDAS. According to the *AmeriPharma Specialty Care* the average cost of IVIG treatments in the United States is \$9,720. If a patient were to undergo four to five infusions per month the

average would be around \$41,796 per month. It was noted in this report that most cannot afford this treatment and one provider deemed the treatment as too experimental to cover the costs. If this treatment were to be mandated under insurance coverage, it would lead to additional costs for all insurers. Rather than mandate coverage on diseases we know little about, we encourage the legislature to find ways for doctors to study and learn more about PANS and PANDAS which could lead to more discoveries of more affordable long-term treatments.

In closing, this legislation is a mandate on insurance providers that could lead to additional costs for insurers. Thank you for the opportunity to testify in opposition to House Bill 2824, and I am happy to answer any questions you might have at the appropriate time.

Report on PANS/PANDAS from the House Committee on Health and Human Services

CHAIRPERSON: Representative Brenda Landwehr

VICE-CHAIRPERSON: Representative John Eplee

RANKING MINORITY LEADER: Representative Monica Murnan

OTHER MEMBERS: Representatives Tory Marie Arnberger, John Barker, Emil Bergquist, Elizabeth Bishop, Doug Blex, Kenneth Collins, Ronald Ellis, Broderick Henderson, Cindy Holscher, Eileen Horn, Ron Howard, Jim Kelly, Megan Lynn, and Kellie Warren

STUDY TOPIC

- Further study of pediatric acute-onset neuropsychiatric syndrome (PANS) and pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections (PANDAS).

House Committee on Health and Human Services

Report

Conclusions and Recommendations:

The Committee heard testimony from conferees urging greater public awareness in Kansas on pediatric acute-onset neuropsychiatric syndrome and pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections (PANS/PANDAS), more education of providers, and expanded payment sources for the treatments discussed, including a state requirement for insurance reimbursements. Enactment of state insurance mandates is a complicated issue requiring review of the federal Patient Protection and Affordable Care Act requirements for State General Fund payments, statutorily required cost benefit analysis, and test tracking of the new benefit mandate on the State Employee Health Plan. In addition, state mandates cover only insured products, so self-insured groups may be exempt under the federal Employee Retirement Income Security Act of 1974 and other groups and associations may be exempt under short-term limited duration plans or exempt under state laws.

The Committee recommends the 2021 Legislature review the insurance implications of any proposed payment mandate on both the public and private payer communities. The Committee directs this report be given to the Senate Committee on Financial Institutions, the Senate Committee on Insurance, and the House Committee on Insurance and Pensions.

Proposed Legislation: None.

BACKGROUND

The Legislative Coordinating Council approved a one-day meeting of the House Committee on Health and Human Services (Committee) during the 2020 Interim to further study pediatric acute-onset neuropsychiatric syndrome (PANS) and pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS). The Committee previously held an informational briefing on PANS/PANDAS on February 4, 2020.

COMMITTEE ACTIVITIES

The Committee met on December 14, 2020.

PANS/PANDAS: Description of Disease, History, and Current Status

A psychiatrist reviewed the three diagnostic criteria for PANS: an abrupt, acute onset of obsessive-compulsive behaviors or severe restricted food intake; concurrent additional behavioral or neurological symptoms with similarly acute onset and severity from at least two of seven behavior categories; and the symptoms are not better explained by a known neurologic or medical disorder. Diagnosis is made based on the child's medical history, as there are no laboratory tests or biomarkers that are completely reliable for diagnosis. Additionally, a PANS diagnosis comes only after all other known illnesses or diseases that could cause the symptoms have been ruled out. She stated PANDAS is a subset of PANS. The progression of PANS/PANDAS depends on triggers, such as viral infection or gluten intolerance. Successful treatment depends on how

quickly the underlying conditions are identified and addressed.

The psychiatrist stated PANS and PANDAS are encephalopathies, which means they are diseases that affect brain function. They also damage the immune system. Usually, when a body fights an infection, it produces antibodies to attack the bacteria. But in PANS/PANDAS patients, the bacteria mimics human molecules, tricking antibodies into attacking human tissue. The body's antibodies attack the basal ganglia, the part of the brain integral to voluntary motor control, cognition and reward processes, executive functioning, behavior and emotions, and dopamine regulation. Viral, bacterial, or fungal agents can all trigger PANS/PANDAS symptoms. The variety of triggers complicates physicians' efforts to identify the source of the symptoms.

The psychiatrist stated most physicians are unfamiliar with PANS/PANDAS. She recommended that efforts to raise awareness of the symptoms and treatment of the conditions be extended to those who work with children often, including pediatricians, family practice physicians, psychologists, and educators. It is estimated that 1 in 200 children each year suffer from PANS/PANDAS, although this number may underestimate the prevalence. The conditions are more common in boys, tend to appear between ages four and nine, and can become chronic. Treatment includes antimicrobial treatment, immunomodulatory treatment, and symptom relief with psychotherapeutic treatments. However, treatments vary according to the severity level of the conditions. Psychotropic medicines can help relieve symptoms, and not all individuals require the more intensive intravenous immunoglobulin (IVIG) treatment.

Testimony from Parents and Individuals on Symptoms and Costs

A parent testified to her work with children as an occupational therapist. She had worked with children who presented with developmental disabilities and coordination issues but may have suffered from PANS/PANDAS. Her child developed severe behavioral symptoms at age four but had to wait four years before being diagnosed with PANDAS. Her family spent more than

\$100,000 out-of-pocket for treatment, including occupational therapy, sensory integration therapy, psychological and psychiatric services, and medical interventions to stabilize the child's decline. The conferee requested the Committee introduce legislation to provide insurance coverage for PANS/PANDAS.

Another parent testified to her experience with a child living with PANS/PANDAS. At age nine, the child suffered an onset of severe behavioral symptoms, curling into a fetal position, running through the house checking locks, agitating through the night, and failing to maintain focus while completing school assignments. Psychotropic medications did not work. Eventually, the parent found a physician who recommended IVIG treatment for the child. The treatment helped but cost the family tens of thousands of dollars.

Another parent testified to her child's experience with PANS/PANDAS. The child spent time in a psychiatric hospital as a result of his severe obsessive-compulsive disorder (OCD). Her son qualified for the Serious Emotional Disturbance Home and Community Based Services waiver. The conferee requested the Legislature establish an advisory council on PANS/PANDAS to educate medical providers and insurance companies about the condition and recommended protocols for treatment and study more effective insurance coverage of specialist-recommended treatments.

A private citizen diagnosed with PANDAS testified to his experiences. Starting in elementary school, he began to develop behavioral symptoms. He was diagnosed with PANDAS at age 15 and participated in an IVIG treatment study. The treatment taxed him but successfully eliminated his anxiety, OCD, and behavioral tics. After treatment, his school performance improved dramatically. He asked the Committee to consider families who could not afford treatment for PANS/PANDAS. His parent testified that his condition appeared after a severe streptococcal infection. After the IVIG treatment study ended, he needed additional treatments. The family's insurance company deemed the IVIG treatments to be experimental and would not cover the services.

A parent of children with neuro-immune diseases testified to her family's experiences. Her son received IVIG treatment after exhibiting multiple mental and physical symptoms and medications did not work. Her daughter also suffered from behavioral and physical attacks, and tests revealed she suffered from a severe case of encephalitis. The brain injury caused by her daughter's own immune system's attack on itself damaged the daughter's developmental growth, forcing her to learn how to walk, crawl, and roll again at nine years of age. The parent recommended Kansas doctors receive more education in neuro-immune illnesses and insurance companies pay for the treatments of these illnesses. She emphasized the importance of identifying the diseases early before they cause more damage.

A private citizen who experienced autoimmune encephalomyelitis (inflammation of the brain and spinal cord) compared his symptoms to feeling like his mind and body were locked, oscillating between non-function and dysfunction. He stated he still struggles with intermittent depression, bouts of feelings of self-harm, and occasional panic attacks.

A family physician stated the earlier doctors diagnose PANS/PANDAS, the better the long-term outcomes and less expensive the treatments will be for patients. He referenced an unpublished survey that asked families about treatment costs related to PANS/PANDAS and autoimmune encephalitis. The summary from the study showed insurance covers only a portion of testing and treatments for the diseases, leaving families with tens of thousands of dollars in out-of-pocket expenses. Parents of children with the illnesses have been forced to borrow, take money from their retirement funds, and declare bankruptcy because of the high costs. His own family's expenses for treating the diseases amounted to \$1.1 million in one year, which did not include alternative care, travel, or supplements. The physician recommended doctors receive more education on PANS/PANDAS and insurance companies be required to cover treatments.

Treatment Options

A rheumatologist described IVIG as a collection of antibodies and noted IVIG treatment is also used for other conditions. IVIG, however, is hard for some families to obtain. Most cannot afford treatment costs themselves. Other treatments are in development, but doctors lack solid enough evidence to recommend them for policy purposes. According to the rheumatologist providing testimony, immunologists, primary care doctors, behavioral health specialists, and the family must all work together to successfully treat the conditions. Research is also being done on whether PANS/PANDAS is a genetic condition since there are some indications that, if autoimmune disorders run in the family, PANS/PANDAS may develop.

An immunologist outlined the initial treatment regimen for PANS/PANDAS, which includes anti-inflammatory medications, antihistamines, antibiotics, and steroids. He stated the difference between PANS/PANDAS and most other behavioral diseases is the former are reactions to an abnormal immune response to an infection whereas the latter are the result of environmental and genetic factors. IVIG is a purified gamma globulin derived from blood plasma from thousands of plasma donors and is also being used as a treatment for COVID-19. He recommended IVIG be reserved for children who do not respond to other treatments because of its high cost. In response to a Committee member's question, the doctor recommended oversight of the use of IVIG because of the enormous cost of the treatment.

The immunologist testified that PANS/PANDAS is difficult to diagnose because it is a newly recognized disease, is still being defined by doctors, resembles other behavioral diseases, and involves the brain, which is also not well understood. Before children are diagnosed with PANS/PANDAS, the immunologist said, the patients should be seen by primary care physicians and psychologists.

International Classification of Diseases-10 Code and Research

The Executive Director of the PANDAS Network reported on a recently published ten-year

study that determined PANS/PANDAS is an autoimmune disease causing encephalitis. She explained the World Health Organization's International Classification of Diseases has published a code, D 89.89, specifically for PANDAS. The code registers PANDAS as an autoimmune disease deserving treatment. She said there has been some resistance from insurance companies in Massachusetts to the new code for the disease. In response to a question from a Committee member, she stated doctors specializing in immunology, infectious diseases, or neurology, and not a pediatrician or family physician, should determine whether to use the new code.

Additional Information and Discussion

The Kansas Legislative Research Department (KLRD) provided additional information for the Committee: the *2020 Kansas Legislator Briefing Book* article on Kansas health insurance mandates, the Kansas State Employees Health Care Commission's "Report on Insurance Coverage for Autism Spectrum Disorder Pilot" and "Report on Insurance Coverage for Amino Acid Based Elemental Formula for Pilot," and copies of enacted bills 2010 Senate Sub. for HB 2160 (regarding coverage for the diagnosis and treatment of autism spectrum disorder and the coverage of orally administered anticancer medications) and 2018 SB 348 (which included provisions regarding coverage for amino acid-based elemental formula).

A Committee member noted the Kansas Medical Society (KMS) determines the curriculum for medical doctors and other groups. The comment was made KMS should be part of the discussion of the illness and treatments.

An Assistant Revisor of Statutes noted that, under current law, before an insurance mandate bill would be drafted, a cost-benefit analysis would be completed through the state employee health plan. After that, a bill could be drafted to mandate insurance coverage for the diseases containing specific details on the treatment modalities covered. Any insurance mandates could not apply to self-insured plans, short-term limited duration plans, and the nonprofit agricultural membership organization incorporated in Kansas

on June 23, 1931, authorized by legislation enacted in 2019 HB 2209. The State would not be able to mandate coverage for any plans that did not fall under the State's oversight.

The Assistant Revisor also reported, if the Kansas State Employees Health Care Commission conducted a cost-benefit analysis of a PANS/PANDAS insurance coverage mandate, the Commission would make a recommendation if it had enough data or recommend the study be extended through the state employee health plan for another year to gather additional data.

CONCLUSIONS AND RECOMMENDATIONS

The Committee requests KLRD staff research other states that have mandated insurance coverage for PANS/PANDAS and provide the findings to the Committee.

The Committee concluded it heard testimony from the conferees that Kansas needed greater public awareness of this condition, more education of providers, and expanded payment sources for the treatments discussed, including a state mandate payment for insurance reimbursements. Enactment of state insurance mandates is a complicated issue requiring review of the federal Patient Protection and Affordable Care Act requirements for State General Fund payments, statutorily required cost benefit analysis, and test tracking of the new benefit mandate on the State Employee Health Plan. In addition, state mandates cover only insured products, so self-insured groups may be exempt under the federal Employee Retirement Income Security Act of 1974 and other groups and associations may be exempt under federal short-term limited duration plans or exempt under state laws.

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