

STATE OF KANSAS
HOUSE OF REPRESENTATIVES

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JOHN R. EPLEE, MD
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Chairman Longbine and esteemed members of the Senate FI & Insurance Committee.
I do appreciate the opportunity to appear before you to update you on HB2110 and where it stands in the legislative process, and I am here to introduce you to the medical diagnoses of PANS and PANDAS, and the importance of moving HB2110 out of committee to the Senate Floor. This bill has already passed favorably out of House Insurance & Pensions and the House Floor on final action 113-8 on 2/22/2022.

PANS stands for Pediatric Autoimmune Neuropsychiatric Syndrome and PANDAS stands for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections. While I was aware of this disorder in my medical training, I was first introduced to the importance of this disease and its treatment options 4 years ago. The proponent you are about to hear from introduced me to the importance of access to required timely but costly treatment(s). This issue did go through the House Health at that time and was sent to an interim study to then be referred to House Insurance and Pensions because of the cost of treatment. This bill was then reintroduced in this past year with a hearing in the House Insurance Committee. A request was made for a Cost Report on the SEHP (State Employees Health Plan); the Segal Study is included with my testimony. I feel it is a most favorable report. The need for this report/study is outlined in KSA 40-2248 & 40-2196.

While many treatments for PANS/PANDAS are approved including steroids, antibiotic cocktails, counseling, etc., treatment with IgG, which is so essential in some cases, is NOT approved by insurance companies. IgG in today's health world can cost from 4-7 thousand dollars per treatment. While very expensive, it is very effective related to a cascade of immunity related responses that cause this disease.

And make no mistake ---in the past this was not a well understood disease. Many physicians felt that these children only had mental health issues. The association with the immune system following a severe infection like strep is clearly the trigger. If other treatments don't work then IgG becomes the 'safety' on the trigger. It clearly always resolves or remarkably improves the symptoms for an extended time.

This is a real disease with an ICD-10 code now attached to it. That is the billing book that physicians' offices use to bill for services. It indicates this is a legitimate disease. Many other states have already passed this very proposal. While a rare disorder and not fully understood yet, Kansas children must gain access to this as a covered treatment through their insurance. Passing this bill out of your committee will provide the next step in that process.

Thank you for your consideration of HB 2110.

Representative John R Eplee, MD, FAAFP, District #63

A handwritten signature in black ink, appearing to read 'John R. Eplee'. The signature is written over the printed name and is enclosed within a hand-drawn oval.

MEMORANDUM

To: Janet Stanek, Director, State Employee Health Plan

From: Segal

Date: November 22, 2021

Re: House Bill No. 2110 – Coverage and prescribed treatment of Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS)

In response to the House Committee on Insurance and Pensions, Segal has researched the potential social and financial impacts of House Bill No. 2110 (HB 2110) on the Kansas State Employee Health Plan (“SEHP”) to provide coverage for the diagnosis and prescribed treatment of PANS and PANDAS for the next coverage year. The impact to claims cost and administrative expenses is expected to be minimal. The estimated annual cost range for PANS/PANDAS treatment is \$211,150 to \$704,500, or 0.06% to 0.19% of total projected plan costs.

Research and data were gathered from various health organizations, as well as other states that have passed, or are pending, legislation related to PANS and PANDAS. Although PANDAS was discovered fairly recently (connection between strep and obsessive compulsive disorder first made in 1986)¹, the science-based information regarding diagnosis and treatment of PANS and PANDAS is consistent throughout the research and data available.

- PANS is a clinical condition defined by the sudden encephalitic-like onset of obsessive-compulsive symptoms (OCD) and/or severe eating restrictions and at least two concurrent cognitive, behavioral, or neurological symptoms. PANS can be triggered by infections, metabolic disturbances, and other inflammatory reactions. It is easiest to understand PANS as an umbrella term for many triggers that create inflammation in the brain, leading to behavioral changes. PANS is a medical disorder with both physical and psychiatric presentations.^{13, 14}
- PANDAS has five distinct criteria for diagnosis, including abrupt “overnight” OCD or dramatic, disabling tics; a relapsing-remitting, episodic symptom course; young age at onset (average of 6–7 years); presence of neurologic abnormalities; and temporal association between symptom onset and Group A strep (GAS) infection. The five criteria are usually accompanied by similar comorbid symptoms as found in PANS.¹³

Two leading physicians specializing in research and treating PANS and PANDAS agree the prognosis is good and PANDAS is a curable disorder^{1, 17}. A group of experienced medical professionals that serve on the Scientific Advisory Board for the PANDAS Physician Network, a Division of the Foundation for Brain Science and Immunology, a nonprofit organization in Mooresville, NC, developed flowcharts for diagnosis and treatment to help clinicians evaluate and determine the best course of treatment. At this time, however, some data in these conditions

remains relatively unknown, and there is concern with symptoms being misunderstood or misdiagnosed.

There are many long-standing treatments, covered by traditional medical benefits and Medicaid that have been used to treat OCD, tic disorders, Attention Deficit Disorder (ADD), and other behavior disorders. Various treatments include antibiotics, steroids, Intravenous Immunoglobulin (IVIg) treatments, plasmapheresis, plasma exchange, Cognitive Behavioral Therapy (CBT), Exposure and Response Prevention (ERP), anti-anxiety medications, and occupational therapy. However, when these symptoms and conditions are diagnosed as being associated with PANS and PANDAS, these same treatments are considered to be experimental and are often not covered by insurance.

With an estimated 1 in 200 children affected, several states have moved toward passing legislation related to PANS and PANDAS. The World Health Organization announced that, effective January 1, 2022, ICD11 diagnosis codes will include a PANDAS-specific code bringing world-wide recognition to the diagnosis.

The following information provides more detail from research findings as pertains to the topics listed in KSA 40-2249a.

Estimated Cost

HB 2110 requires SEHP to provide coverage for PANS and PANDAS to eligible dependents. Below, is a brief summary of the estimated cost.

Estimated Costs per PANS and PANDAS Treatment		
Treatment Type	Avg Costs per Treatment	Severity Mix (est)
Mild: High-dose antibiotics to clear/prevent Group A Strep (GAS)	\$5,000	50%
Moderate: Antibiotics & IVIg treatment	\$16,972	45%
Severe: Antibiotics & IVIg treatment & Therapy	\$33,944	5%
Weighted Avg of Treatment Costs (listed above)	\$11,835	

Assumes one treatment per year

Estimated Cost of Providing PANS and PANDAS Coverage					
Prevalence Percentage*	Enrollment Ages 3 to 14**	Prevalence Count	Avg Cost of Treatment	Estimated Annual Treatment Costs	Percentage of Total 2021 Projected Plan Cost
0.50% (1 in 200 rate)	11,904	60 (11,904*0.50%)	\$11,835	\$704,500	0.19%
0.15%	11,904	18 (11,904*0.15%)	\$11,835	\$211,150	0.06%

*1 in 200 rate is an estimated "lifetime prevalence"; utilization in any one year can be lower

**Eligibility: as of July 2021 Cerner eligibility data

Please note the updated research will differ from the figures in the fiscal note previously provided by the Division of the Budget.

Original calculations from the Division of the Budget were based on the full enrolled population of 25,715 members; whereas, the more recent research suggests that PANS and PANDAS typically occurs in children, ranging in age from 3 to 14 years, at an estimated prevalence of 0.50%, or 1 in 200 children.^{5, 6, 13}

Updated treatment cost estimates are based on the narrowed count of 11,904 enrolled children, ranging in age from 3 to 14 years, and is provided on a range of prevalence estimates - from 0.15% to 0.50% - based on a combination of antibiotic and Intravenous Immunoglobulin (IVIg) treatments, according to condition severity. IVIg is a therapy treatment for patients with antibody deficiencies.

Immunoglobulins are made by the immune system of healthy people for the purpose of fighting infections. Intravenous immunoglobulin (IVIg) is a blood product prepared from the serum of between 1,000 and 15,000 donors per batch. IVIg is used to treat various autoimmune, infectious, and idiopathic diseases. The highest utilizing clinical specialties of IVIg are neurology, haematology, immunology, nephrology, rheumatology and dermatology. IVIg has had a major impact on the treatment of neurological disorders including dermatomyositis, Guillain–Barre syndrome, chronic inflammatory demyelinating polyneuropathy (CIDP), multifocal motor neuropathy (MMN), myasthenia gravis and stiff person syndrome.

Social Impact

A. The extent to which the treatment or service is generally utilized by a significant portion of the population;

Looking at the SEHP population, the assumption is that 60 children between the ages of 3 to 14 would be affected with PANS/PANDAS. This calculation is based on 11,904 children within the age range of 3 to 14 years, currently enrolled in the SEHP plans, and the assumption that 1 in 200 children is affected. If the age range is expanded to 17 years, the currently enrolled count increases to 17,335, and the prevalence count increases to 87.

On a national level, according to the U.S. Census Bureau, in 2021, there are approximately 74.1 million children in the U.S. who are 17 years of age or younger. Assuming a 0.50% (1 in 200) prevalence rate, we estimate that 370,689 children could potentially be affected by PANS/PANDAS. This population is projected to increase 2.4% by 2031 and by an additional 1.7% by 2041.

- The U.S. Census Bureau projected child population table (in millions): (<https://www.childstats.gov/AMERICASCHILDREN/tables/pop1.asp>)

Ages (0-17)	2021	2031	2041
All ages (0-17)	74.1	75.9 (1.8 diff) 2.4% increase	77.2 (1.3 diff) 1.7% increase
Ages 0-5	24.6	25.2 (0.6 diff) 2.4% increase	25.4 (0.2 diff) 0.7% increase
Ages 6-11	24.3	25.5 (1.1 diff) 4.6% increase	25.7 (0.2 diff) 0.8% increase
Ages 12-17	25.2	25.2 (0 diff) 0% increase	26.1 (0.9 diff) 3.7% increase

Additional statistics:

- PANS/PANDAS prevalence:
 - Age at Onset: 11% at 1 to 3 years; 69% at 4 to 9 years; 19% at 10 to 13 years; and 1% at 14+ years ⁵
 - Primary Symptoms: 37% with OCD; 14% with TICS; and 49% with BOTH
 - PANS/PANDAS population overview: ⁵
 - Young age at onset: 6.5, +/- 2 years for Tics; and 7.4, +/- 2 years for OCD
 - In general, the ratio for boys to girls is 2.6:1 ; below age 8 years, the ratio of boys to girls is 4.7:1
 - Approximately 500,000 children are diagnosed with OCD in the U.S. ⁵
 - Approximately 138,000 children are diagnosed with Tourette Syndrome in the U.S. ⁵
 - 1.5 million+ children were diagnosed with serious anxiety/phobia/OCD/bipolar in a given year (1994-2011)
- 10% of all pediatric hospitalizations are attributed to mental health conditions.¹¹
- An estimated 20% of children and adolescents in the U.S. meet diagnostic criteria for a mental health disorder.¹¹
- The CDC reports that attention deficit hyperactivity disorder (ADHD), behavior problems, and depression were the most commonly diagnosed mental disorders in children.¹⁰

B. The extent to which such insurance coverage is already generally available;

Although traditional insurance benefits and Medicaid cover treatment for various behavior and tic disorders that are tied to more prevalent diagnoses, when these symptoms and conditions are diagnosed as being associated with PANS and PANDAS, these same treatments are considered to be experimental and are often not covered by insurance. In recent years, as awareness of the condition has grown, several states have moved toward passing legislation related to PANS and PANDAS.

- In 2017, Illinois became the first state to pass legislation requiring coverage of treatment for PANS/PANDAS. Delaware, Indiana, Maryland, Minnesota, and New Hampshire later followed with Massachusetts being the most recent, having a January 1, 2022 effective date. Texas and Arkansas passed legislation forming an advisory team/council to provide guidance on protocols for research, diagnosis, and treatment.¹²
- The following states have proposed legislation to cover PANS/PANDAS treatment and are either pending or have not yet made it successfully through the process: Iowa, Maine, New York, Oregon, Ohio, Rhode Island, and West Virginia. ¹²
- Currently, there is no specific ICD-10 diagnosis code for PANS or PANDAS. The D89.89 code is a valid billable ICD-10 diagnosis code for *Other specified disorders involving the immune mechanism, not elsewhere classified*, but based on information from the state of Illinois, causes issues with insurance codes not recognizing the disorders as PANDAS, ¹²
- Effective January 2022, the ICD-11 diagnosis codes will include the PANDA-specific code 8E4A.0 *Paraneoplastic or autoimmune disorders of the central nervous system, brain or spinal cord*. Also included will be ICD-11 diagnosis code 8A05.10 *Infectious or post-infectious tics*.

- C. If coverage is not generally available, the extent to which the lack of coverage results in persons being unable to obtain necessary health care treatment;

Lack of awareness, misunderstanding, and misdiagnosing PANS/PANDAS can have detrimental and long-term consequences on both the physical and mental condition of a child. Not only do the children develop chronic illness, but the OCD and tic disorders also impact their social behaviors such as not attending school, withdrawing from friends and family, and other activities they normally enjoyed doing, and can lead up to death. (ex. suicide, accidents by impulsive behavior).¹⁰. 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.

- Early detection may prevent up to 25-30 percent of childhood mental illnesses¹³
- “Data from an unpublished survey of over 1,000 parents of children with PANS and/or PANDAS, conducted by Moleculera Labs in 2018, “Economic and Psychosocial Costs of PANS and PANDAS,” revealed that, on average, patients have seen up to 12 medical providers, resulting in an approximate 3-year delay in receiving a diagnosis of PANDAS or its broader diagnostic category, PANS (Pediatric Acute-onset Neuropsychiatric Syndrome). 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.”

- D. If the coverage is not generally available, the extent to which the lack of coverage results in unreasonable financial hardship on those persons needing treatment;

There are many articles describing the hardships faced by families trying to find the care needed for their child, and having to pay for coverage out of their own pockets. Average costs range from \$5,000 to \$33,944, with one family reaching \$100,000 in out-of-pocket costs. The majority of families faced having to establish ‘GoFundMe’ accounts, request loans from parents (grandparents) and other relatives, refinance their home, sell a vehicle or furniture, or quit their jobs as they could not afford a caretaker.^{15, 16, & 17}

Per PANDAS advocate, Wendy Nawara, *“PANDAS treatment attacks the things that need to be attacked as opposed to attacking a portion of the child's brain. Yes, it is extremely expensive. Like you said, up to \$15,000. It is dose-based on the weight of the child. So honestly, the longer we wait to treat these kids, they grow bigger and the more expensive that treatment becomes. And if a doctor has inadvertently missed it, or if an insurance company puts roadblocks up in front of a family for a year at a time — what could have been solved with perhaps a \$5,000 treatment becomes that \$15,000 treatment.”*¹⁸

- E. The level of public demand for the treatment or service;

The House Committee on Health and Human Services Report dated January 2021 listed six parents and private citizens that provided testimony on symptoms, along with one psychiatrist, one rheumatologist, and one immunologist testifying for the demand of the treatment.

Over half the states in the U.S. have Proclamations/Resolutions issued for PANS/PANDAS Annual October 9th Awareness Day (some are Permanent Proclamations/Resolutions), and approximately 10 states with requests filed.⁵ This is in addition to the nine states with PANS/PANDAS-related legislation and the seven with pending/attempted legislation, mentioned before.

- F. The level of public demand for individual or group insurance coverage of the treatment or service;

Please refer to the information provided under Social Impact, item B. Treatments associated with PANS/PANDAS are often considered to be experimental and are not covered by insurance. In recent years, as awareness of the condition has grown, several states have moved toward passing legislation related to PANS and PANDAS.

- G. The level of interest of collective bargaining organizations in negotiating privately for inclusion of this coverage in group contracts; and

There were no findings specific to collective bargaining activity for PANS and PANDAS treatment.

- H. The impact of indirect costs, which are costs other than premiums and administrative costs, on the question of the costs and benefits of coverage.

As referenced under Social Impact, items A, C, and D, indirect costs include excessive travel, unnecessary medical bills, and anxiety due to the many physician visits, diagnostic testing, medications, etc., as a result of misdiagnosis. Many parents have had to borrow money from relatives, quit their jobs to care for their children, and homeschool their children. The children suffer unnecessarily from misdiagnoses, diagnostic testing, ineffective medication, social stigma, etc. The associated stress and anxiety results manifest in additional physical and mental health issues.¹⁵

Additional commentary relative to PANS/PANDAS:

- "A disease that manifests as psychiatric symptoms but doesn't respond to psychiatric medications"¹⁵
- "Tests (ex. brain MRI) kept coming back normal. Neurologists referred him to psychiatrists. Psychiatrists referred him back to neurologists. Pediatricians recommended therapists. Therapists suggested psychologists."¹⁶

Financial Impact:

- A. The extent to which insurance coverage of the kind proposed would increase or decrease the cost of the treatment or service;

The longstanding recommended treatment for PANS/PANDAS includes a combination of antibiotics, IVIg, and possible therapy. The appropriate combination of medication and number of treatments depends on the severity of the condition. As noted early in this memorandum, cost estimates, according to severity of condition, range from \$5,000 to just

under \$34,000 per treatment, with a weighted average per-treatment cost approximately \$12,000, as most cases fall into the mild to moderate level of severity. These treatments are currently available and are frequently utilized to treat other autoimmune, immune-deficient, and chronic inflammation conditions. Insurance covers these treatments for those types of conditions. Extending insurance coverage for treatment of PANS/PANDAS is unlikely to impact the actual billed cost of the treatment; however, it would have a significantly positive impact on the affordability of treatment and quality of life for those families impacted by PANS/PANDAS.

B. The extent to which the proposed coverage might increase the use of the treatment or service;

Providing coverage for treatment of a condition that was previously not covered will certainly increase the use of the treatment. The incidence of PANS/PANDAS is fairly low, impacting approximately 1 in 200 children between the ages of 3 and 14 years. However, early diagnosis and treatment is ideal, and will greatly reduce the incidence of chronic and more costly conditions likely to have occurred with longer term misdiagnoses and mistreatment.

- PANDAS Diagnostic Flowchart and Treatment Guidelines
<https://www.pandasppn.org/flowchart/>

C. The extent to which the mandated treatment or service might serve as an alternative for more expensive treatment or service;

As noted under Financial, item B, early diagnosis and treatment with the longstanding protocol of antibiotics and IVIg, is preferable and much less costly in the long run. Appropriate and timely treatment will greatly reduce the incidence of chronic and more costly conditions likely to have occurred with longer term misdiagnoses and mistreatment.

Based on 11,904 children between the ages of 3 and 14 years, currently enrolled in the SEHP plans, and assuming PANS/PANDAS prevalence of 1 in 200, Segal estimates 60 children may be impacted by PANS/PANDAS. Ideally, all 60 of those children would fall into the Mild severity range and receive an early diagnosis and appropriate treatment. If all PANS/PANDAS cases fell into the Mild category, treatment costs would be approximately \$718,320 less costly than if all had fallen into the Moderate category, and \$1,736,640 less costly than if all had fallen into the Severe category.

7/2021 Eligible from Cerner	Prevalence (1 in 200=.50%)	Avg Cost per PANS/PANDAS Treatment (assumes 1 treatment per year)	Projected Annual Cost	Notes
11,904 ages 3 to 14	60	\$5,000 avg cost for all 60 Mild Treatment	\$300,000	Ideal costs if all instances are mild and diagnosed/treated early
11,904 ages 3 to 14	60	\$16,972 avg cost for all 60 Moderate to Severe Treatment	\$1,018,320	\$718,320 diff Mild vs Moderate
11,904 ages 3 to 14	60	\$33,944 avg cost for all 60 Severe Treatment	\$2,036,640	\$1,736,640 diff Mild vs Severe

Additional treatment statistics:

- The National Institute of Mental Health (NIMH) estimates 25-30 percent of childhood mental illness may be preventable through appropriate treatment of PANS and PANDAS.
- "Several case studies into IVIg have confirmed IVIg's efficacy one year following treatment. A 2018 longitudinal study had a follow-up time of up to 4.8 years, and 88% did not experience "clinically significant obsessive-compulsive symptoms" within the follow-up time."⁹
- "For many patients, one course of IVIg is enough to reduce symptoms and even reverse PANDAS."⁸
- "The data reported suggest that early and aggressive treatment of infection may decrease both the likelihood of residual symptoms and the likelihood of recurrence, potentially preventing the high levels of functional impairment seen particularly in the postpubertal years. Having increased vigilance for new infections and exposure to group A Streptococcal infections (GAS) is likely also helpful to minimize the impact of recurrence of PANS symptoms."¹⁰

- D. The extent to which insurance coverage of the health care service or provider can be reasonably expected to increase or decrease the insurance premium and administrative expenses of policyholders; and the impact of this coverage on the total cost of health care.

The impact to claims cost and administrative expenses is expected to be minimal. The estimated annual cost range for PANS/PANDAS treatment is \$211,150 to \$704,500, or 0.06% to 0.19% of total plan costs, based on the lowest and highest prevalence estimates.

Sources:

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3. International Classification of Diseases 11th Revision: <https://icd.who.int/en>
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5. PANDAS Network: <https://pandasnetwork.org/get-involved/statistics/> & <https://pandasnetwork.org/get-involved/awareness-day/>
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Certification

The projections in this report are estimates of future costs and are based on unaudited information available to Segal at the time the projections were made. Projections are not a guarantee of future results. Actual experience may differ due to, but not limited to, such variables as changes in the regulatory environment, local market pressure, changes in group demographics, overall inflation rates and claims volatility. The accuracy and reliability of health projections decrease as the projection period is extended.

By signing below, I certify that I am a qualified actuary by education and experience to evaluate health reserves and funding practices. I am a Fellow of the Society of Actuaries and a member of the American Academy of Actuaries and certify that all analysis was conducted in accordance with all applicable Actuarial Standards of Practice. All sections of this report are considered an integral part of the actuarial opinion.



Patrick Klein, FSA, MAAA
Vice President



Gina Sander, FLMI
Vice President, Senior Consultant