

## MINUTES

### HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES

December 14, 2020  
Room 112-N—Statehouse

#### Members Present

Representative Brenda Landwehr, Chairperson  
Representative John Eplee, Vice-chairperson  
Representative Tory Arnberger  
Representative John Barker  
Representative Emil Bergquist  
Representative Elizabeth Bishop  
Representative Doug Blex  
Representative Kenneth Collins  
Representative Ronald Ellis  
Representative Broderick Henderson  
Representative Cindy Holscher  
Representative Eileen Horn  
Representative Ron Howard  
Representative Jim Kelly  
Representative Megan Lynn  
Representative Kellie Warren

#### Members Absent

Representative Monica Murnan, Ranking Minority Member

#### Staff Present

Iraida Orr, Kansas Legislative Research Department (KLRD)  
Marisa Bayless, KLRD  
Eileen Ma, Office of Revisor of Statutes  
Sky Westerlund, Committee Assistant

#### Conferees

Tara Richardson, MD, Psychiatrist (*via Zoom*)  
Andi Bonge, BSEd, Master of Occupational Therapy (*via Zoom*)  
Shannon Wright, Parent  
Melanie Musselman, Parent  
Mason Lough, Private Citizen  
Carrie Lough, Parent  
Shirley Wang, MD, Rheumatologist (*via Zoom*)  
Roger Kobayashi, MD, Immunologist, PANS/PANDAS Researcher (*via Zoom*)  
Diana Pohlman, Executive Director, PANDAS Network (*via Zoom*)

Micaela Widman, Parent  
Kai Widman, Private Citizen  
Jerad Widman, MD, Parent

## Others Attending

See [Attached List](#).

## ALL DAY SESSION

### Welcome

The Chairperson opened the Committee meeting at 9:06 a.m. Technical difficulties caused a delay, and the Committee began hearing testimony at 9:20 a.m. Recording difficulties continued until 10:13 a.m.

### **PANS and PANDAS: Description of Disease, History, and Current Status and Testimonies from Parents and Individuals**

Tara Richardson, MD, Psychiatrist, joined the Committee meeting *via* Zoom. Dr. Richardson described Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and the three diagnostic criteria: 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. Behaviors can include obsessions such as washing hands or intense fear of food or acting like a much younger individual. Dr. Richardson explained the diagnosis is made based on the child's medical history, as no lab tests or biomarkers are fully reliable for diagnosis. She explained further the PANS diagnosis is one of exclusion, meaning that all other known illnesses or diseases that could cause the symptoms have been ruled out.

Dr. Richardson stated Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) is a subset of PANS. She further stated most studies are centered around PANDAS due to the similarity to a different known medical phenomenon called Sydenham chorea. Dr. Richardson noted, in an infection, the body produces antibodies, and the antibodies go after the infection. But with PANS/PANDAS, the bacteria puts antigens on its cell wall that look like the human host. The antibodies in the brain recognize these antigens but cannot distinguish the infection from human tissue and begin attacking the human tissue. In the case of PANS, the antibodies attack the neurons in the part of the brain called the basal ganglia. The basal ganglia is involved in voluntary motor control, cognition and reward processes, executive functioning, and behavior and emotions, and is the location of most of the dopamine neurons in the brain and the target of most antipsychotic medications. She further stated PANS and PANDAS are encephalopathies, which means they are diseases that affect brain function. Diagnostic guidelines to clarify the condition of PANS/PANDAS were published in the *Journal of Child and Adolescent Psychopharmacology* in 2017. She stated it takes time for such information to make its way into medical teaching, knowledge, and curriculum ([Attachment 1](#) and [Attachment 2](#)).

Dr. Richardson stated parents have a difficult time describing the breadth of the behaviors, and most physicians are unfamiliar with the syndrome. She stated parents may be advised their child has a developmental issue or a psychiatric disorder. She said it is estimated 1 in 200 children each year are afflicted with PANS. It is more common in boys than girls, with the peak onset from ages four to nine. An estimated 65 percent of PANS patients have a relapsing/remitting course, meaning the symptoms may improve or be gone, but then later return. Cumulative damage occurs, creating a chronic condition. Dr. Richardson stated the treatment is a three-pronged approach of antimicrobial treatment, immunomodulatory treatment, and symptom relief with psychotherapeutic treatments. Dr. Richardson went on to share her personal experience as her kindergarten-aged child, over a three-day period, developed a textbook presentation of PANS. The child exhibited, to a moderate or severe degree, 19 of 23 symptoms. Dr. Richardson described the difficulty in obtaining care for her daughter. She stated early diagnosis and treatment would ease the suffering of these children and the extreme burden on their families.

Andi Bonge, BSEd and Master of Occupational Therapy, addressed the Committee *via* Zoom. Ms. Bonge stated she is licensed to practice occupational therapy in Missouri and has worked with children in school settings since 2000, specializing in children with sensory and behavioral disorders. She stated her work has enabled her to witness children with symptoms in the school setting and how the diagnosis may be missed by medical practitioners. She noted she has worked with children who presented with developmental disabilities and coordination issues, but she now believes they may have had PANDAS. Ms. Bonge's youngest daughter, at age four, developed severe behavior symptoms. It took four years for a diagnosis of PANDAS and, by that time, her daughter met the criteria for Autism Level I. Ms. Bonge stated they spent over \$100,000 out-of-pocket for interventions, including occupational therapy, sensory integration therapy, psychological and psychiatric services, and medical interventions to stabilize her daughter's decline. Ms. Bonge asked the Committee for a bill to provide insurance coverage for children in the state of Kansas with PANS/PANDAS ([Attachment 3](#)).

Shannon Wright, parent of a child with PANDAS, testified before the Committee. Ms. Wright stated, in 2011, her then nine-year-old daughter suddenly displayed extreme behaviors from curling into a fetal position to running through the house checking locks. Ms. Wright explained her daughter lost her ability to maintain her concentration and complete assignments. Her daughter stayed awake and agitated through the night. The family pediatrician referred the child to the local mental health center, where a psychiatrist saw the child weekly and ordered blood work and other tests. They tried psychotropic medications without the hoped-for results. Ms. Wright stated a neurologist ordered more tests. She stated how the stress was affecting the entire family. Searching the Internet, Ms. Wright discovered PANDAS and began to read articles about the condition; through her searching, she found a doctor in Chicago who suggested intravenous immunoglobulin (IVIG) treatment for her child. The family paid \$10,000 for the first IVIG treatment and \$12,000 for a subsequent treatment done locally when her daughter had a regression in middle school. Ms. Wright noted her daughter is now a senior in high school and plans to attend college next year. Ms. Wright stated none of her daughter's success would have been possible without the treatment she received ([Attachment 4](#)).

Melanie Musselman, parent of a child with PANS, spoke about the experiences of her son, who has PANS with severe obsessive compulsive disorder (OCD) and high-functioning autism. Ms. Musselman stated, until her son was 14 years old, he was mostly an A student who excelled in several subjects and was active in the community and church. In February 2016, his OCD became unmanageable, and by June, he spent 11 days in a psychiatric hospital. Ms. Musselman stated her son qualified for Medicaid on the Serious Emotional Disturbance Waiver and received services through Amerigroup, one of three Medicaid managed care organizations

at the time. By November 2016, her son was admitted into Lakemary, a psychiatric residential treatment facility, and stayed until August 2017. She stated Amerigroup paid about \$13,000 a month for the residential care and treatment at Lakemary. In July 2017, a doctor in Omaha, Nebraska, confirmed her son had PANS. Ms. Musselman went on to describe the multiple treatments and continued difficulties. She stated a conservative cost of treating her son for PANS/PANDAS was \$564,000, including multiple IVIG infusions at a cost of approximately \$180,000. Her son is now a senior in high school and will graduate in May 2021. Ms. Musselman 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 better insurance coverage of specialist-recommended treatments ([Attachment 5](#)).

Mason Lough, private citizen who developed PANDAS, testified before the Committee. Mr. Lough stated he grew up with PANDAS. From elementary school into his freshman year in high school, he was often isolated from others and spent time after school as discipline for vocal tics and other behaviors. He stated he was 15 years old before PANDAS was identified and he qualified for a study. The study involved receiving six rounds of IVIG treatment. Mr. Lough stated his family would drive six hours to Omaha for an all-day treatment for which he would sit in a room and receive intravenous therapy. He described the first few rounds of treatment as being brutal, but the treatment began to work. His anxiety and OCD were gone, and the various tics were reduced. Mr. Lough stated, after the IVIG treatments, he became a Kansas Governor's Scholar, was active in drama and marching band, and earned a full-ride scholarship to college. Mr. Lough stated, had he not qualified for the study, he would not have been able to obtain the IVIG treatment because it is astronomically expensive. He asked the Committee to consider families who may not be able to find treatment for their child because they could not afford the treatment ([Attachment 6](#)).

Carrie Lough, parent of a child with PANDAS, presented her testimony to the Committee. Her son, Mason, was six years old and recovering from a nasty case of strep throat and pneumonia. She stated one afternoon her son became upset and afraid to go anywhere without his parents, had terrifying night terrors, and exhibited noise tics that he could not stop. She stated a neurologist said Mason would grow out of the behaviors. She stated they saw multiple professionals, including specialty doctors and psychologists. One doctor suggested Mason was possessed and another doctor said Mason had multiple, complex mental disorders and prescribed antipsychotic drugs. Ms. Lough stated when her son was 15, they found a doctor in Omaha, Nebraska, who explained the symptoms of PANDAS and prescribed antibiotics, steroids, and allergy medications, and these were helping her son. Her son participated in a study in which he received IVIG treatments. When the study ended, and her son needed more treatments, the insurance labeled the IVIG treatments as experimental and refused to pay. She stated she wondered if his symptoms would ever subside. Eventually, other treatments helped to level out his symptoms. Today he is on a pre-medical education track in college. Ms. Lough suggested medical staff should be informed of the disease and treatments need to be accessible to children with the disease ([Attachment 7](#)).

The Chairperson noted the written-only testimony from Suzanne Wandling ([Attachment 8](#)).

The Chairperson asked the Committee members for their questions for any of the conferees. Responses included:

- Dr. Richardson responded that magnetic resonance imaging (MRI) is not generally helpful in identifying PANS/PANDAS. She stated in some research

facilities, a particular kind of MRI with specific weightings is used and specially trained radiologists review the basal ganglia area of the brain.

- Dr. Richardson stated the range of the natural progression of PANS/PANDAS generally depends on triggers, such as a viral infection or gluten intolerance. An underlying metabolic disorder, that is not identified, may affect the progression. She stated much depends on how quickly the underlying cause is identified and addressed.
- Dr. Richardson stated physicians in Kansas are getting some training in PANS/PANDAS. Further knowledge is gained through resident programs. She stated it was also necessary to work with faculty so they accept and acknowledge the diagnosis. Additionally, there should be awareness of the condition in areas of primary medicine, such as pediatrics, family practice, psychology, and education, as the professionals in those areas are the front-line people working with children who have PANS/PANDAS.
- Dr. Richardson responded that treatment guidelines suggest mild, moderate, or severe levels of the disease and the starting treatments for each corresponding level. She stated psychotropic medicines can help relieve symptoms, and not all individuals would need the IVIG treatment.
- Dr. Richardson affirmed disease triggers can be viral; bacterial, such as strep; or fungal, such as the mold in both the environment and in the home. The variety of triggers makes it very difficult to identify exactly what triggers are affecting each individual. Many studies are being conducted, and some may include following patients into adulthood to determine the long-term effects of the disease.
- Dr. Richardson responded PANS/PANDAS affects the immune system, and it is not known whether the immune system will be permanently compromised or will fully recover. As one grows older, the immune system does become stronger, although autoimmune conditions are generally increasing.
- Ms. Wright stated she and others want better training for physicians and insurance coverage for treatment, especially the IVIG treatment, for those who need it. Ms. Musselman added their family's insurance considered the treatment to be experimental and would not pay for it. However, their child's Medicaid managed care organization, UnitedHealthcare, did pay for the treatment.
- Ms. Bonge stated during the course of an individualized education plan, there cannot be any talk of medical diagnoses, including sharing pamphlets or literature about any diagnosis. Ms. Wright added educational staff could suggest websites or visiting the family doctor, but physicians may or may not be knowledgeable of PANS/PANDAS or people may not necessarily be able to pursue the expensive treatments due to their economic circumstances. Andi Bonge confirmed, in her experience, physicians may not necessarily be able to help the families.

- Dr. Richardson responded it is estimated 1 out of 200 children are likely to have PANS/PANDAS, but it may be an under-estimation as the condition is likely under-diagnosed.
- Ms. Musselman stated the Cunningham Panel costs about \$950 out of pocket, so her son was unable to obtain the test. Dr. Richardson added it is a useful test, but not widely used. The Cunningham Panel is named after a researcher in Oklahoma, and it can help identify the level of autoimmune antibodies in the brain as a means of diagnosing PANS or PANDAS.
- Dr. Richardson stated the estimate of 1 in 200 with PANS/PANDAS includes individuals under 18 years of age.

### Treatment Options

Shirley Wang, MD, Rheumatologist, joined the Committee meeting *via* Zoom. Dr. Wang explained Group A  $\beta$ -hemolytic *Streptococcus pyogenes* are associated with post-infectious autoimmunity, and PANDAS impacts the brain. She stated the clinical management of PANS/PANDAS guideline is from the *Journal of Child and Adolescent Psychopharmacology* published in 2017. She identified the treatments for the clinical management of mild to moderate to severe PANS/PANDAS, as well as the timely evaluation to determine the need for the IVIG treatment. Dr. Wang described IVIG treatment as a collection of antibodies, and noted it is a type of treatment also used for other conditions. Dr. Wang stated it is difficult to obtain treatment, and it is especially hard for physicians and families to know treatment is available but not be able to get it. Some families can self-pay for the treatment, but most cannot. She discussed autoimmune inflammatory diseases, including stating that 40 percent of PANS/PANDAS patients have concurrent inflammatory arthritis. Dr. Wang concluded her testimony noting it takes teamwork among immunologists, primary care providers, behavioral health providers, and others working with the patient and the patient's family ([Attachment 9](#)).

The Chairperson asked the Committee members for their questions. Dr. Wang responded to those questions:

- New treatments, beyond the IVIG treatment, are being developed and tend to be expensive treatments, some requiring hospitalization. The treatments may or may not be used as follow-up to IVIG treatments. Research is occurring, but it is too early to draw accurate conclusions for policy purposes; and
- Studies are being conducted and published that look at the genetics of the disease to see if it runs in a family. Some increased risk to develop psychiatric responses has been seen in families. If others in the family have autoimmune disorders, PANS/PANDAS may develop. Dr. Wang stated, in her practice, about 10 percent of siblings are developing PANS/PANDA, which may be a high estimate.

The Chairperson thanked Dr. Wang for the information.

## Working Lunch

The Chairperson recessed the meeting at 11:39 a.m. for a working lunch.

## Treatment Options, Continued

The Committee reconvened at 12:03 p.m. There was some technical delay and testimony began at about 12:07 p.m.

Roger Kobayashi, MD, joined the Committee meeting *via* Zoom. Dr. Kobayashi is an immunologist in private practice in Omaha, Nebraska ([Attachment 10](#)). He stated the problem of PANS/PANDAS is increasing. The initial treatments involve anti-inflammatory medications, antihistamines, antibiotics, and steroids. Dr. Kobayashi stated the primary indicator of PANS/PANDAS is the sudden abrupt onset of behaviors that are extreme and sometimes make the child feel suicidal. Most behavioral diseases are thought to be largely environmental through family upbringing. The difference with PANS/PANDAS is the behaviors are a reaction coming from an abnormal immune response to a viral or bacterial infection that inflames the basal ganglion in the brain, and the immune system attacks the inflamed basal ganglion instead of reducing the inflammation. The basal ganglion controls mood and emotion, behavior, procedural learning, motor movements, cognition, and sensory reactions. An inflamed basal ganglion is thought to cause the abrupt changes in behaviors. Dr. Kobayashi stated PANS is difficult to diagnose because it is a new disease and it is still being defined; the manifestation of the disease is behavioral, which can look like other disorders; and the disease involves the brain, which is still not well understood. Treatment can be difficult because the disease is not fully understood. He explained IVIG is a highly purified gammaglobulin derived from the plasma of thousands of plasma donors, and the gammaglobulin are antibody proteins that help fight infection ([Attachment 11](#) and [Attachment 12](#)). Gammaglobulin is anti-inflammatory and immunity modulating. Dr. Kobayashi noted gammaglobulin is being used for the treatment of COVID-19. He noted there has been a shortage of gammaglobulin in 2019 and 2020. He stated IVIG should be reserved for children who do not respond to other treatments because of the high cost of the IVIG treatment. Dr. Kobayashi stated funding has become available, and he will be involved in research on varying dosages of IVIG for PANS/PANDAS treatment and whether biomarkers can be identified to help diagnose the disease. Dr. Kobayashi asked the Committee to provide the chance for the children for whom IVIG is warranted to try the treatment. He provided background information for the Committee on PANS/PANDAS ([Attachment 13](#), [Attachment 14](#), and [Attachment 15](#)).

The Chairperson asked the Committee members for any questions or comments. Dr. Kobayashi responded to questions and comments:

- The two-year international study was set to begin in 2019, but was delayed due to several European countries working out details and then the COVID-19 pandemic hit. Stanford University; University of California, Los Angeles; Harvard University; Columbia University in the City of New York; Johns Hopkins Medicine; and the University of Nebraska will participate. The study is anticipated to begin sometime in 2021;
- The diagnosis for PANS/PANDAS is a diagnosis of exclusion because children have all kinds of behavior problems. Before determining whether a child has PANS/PANDAS, the child should be seen by primary care physicians and

psychologists. By the time children come to his attention, it is because everything else has been tried. Pushback about the legitimacy of PANS/PANDAS is coming from those practicing in the areas of infectious disease and neurology. Dr. Kabayashi stated much more is known about the disease than was known five years ago. He restated other treatments must be tried before using IVIG; and

- Some type of oversight is needed regarding the use of IVIG, due, in part, to the enormous cost of the treatment. He suggested patients must be selected and all other behavioral treatments and interventions must have been tried and failed. He stated, generally, improvements are gained with three IVIG treatments, although some individuals may need fewer and others may need more.

The Chairperson thanked Dr. Kobayashi for his testimony.

### **International Classification of Diseases-10 Code; Yale and Columbia Research**

Diana Pohlman, Executive Director, PANDAS Network, joined the Committee meeting *via* Zoom. She founded the organization in 2013 after two of her children developed PANDAS following strep infections. She stated her two children each needed one IVIG treatment. She stated a report of a ten-year-long study has been recently published with breakthrough evidence that PANS/PANDAS is an autoimmune disease causing encephalitis. Ms. Pohlman explained the World Health Organization's International Classification of Diseases has published a code specifically for PANDAS. The code is D 89.89, and it states PANDAS is an autoimmune disease deserving treatment. Ms. Pohlman stated in Massachusetts there has been some pushback from Blue Cross Blue Shield and other for-profit insurers who do not favor the new code.

In response to a question about who should be using the new code, Ms. Pohlman stated a doctor specializing in immunology, infectious diseases, or neurology should determine whether to use the new code and not a pediatrician or a family physician. She stated she has been advised the new code is coupled with an additional code involving autoimmune encephalitis and post-infectious encephalopathy.

A question was asked about which states require payment for the treatment of PANDAS. Ms. Pohlman stated seven states currently mandate insurance coverage of PANDAS.

Ms. Pohlman showed a seven-minute video. The video illustrated and explained the science of what happens with PANS/PANDAS. The strep infection moves into the brain through the nose and causes inflammation in the basal ganglion, which causes the sudden and abrupt onset of behaviors. Ms. Pohlman added the progression of the infection to the psychiatric symptoms occurs in about 72 hours. Ms. Pohlman said IVIG treatments reduce the inflammation in the brain, and patients improve ([Attachment 16](#)).

There were no further questions, and the Chairperson thanked the conferee.

### **Treatment Costs, International Classification of Diseases-10 Code Confirmation, and Recommendations**

Micaela Widman, parent of children with neuro-immune illnesses, testified before the Committee. Ms. Widman described her oldest son, from a very early age, as extremely strong-

willed and challenging. But when he was 12 years old, her son took a sudden and devastating turn, exhibiting multiple mental symptoms as well as multiple physical symptoms. He was admitted into a psychiatric hospital, but medications seemed to make his symptoms worse. Ms. Widman stated they went through many more doctors and health offices, most of whom did not accept insurance. The Cunningham Panel test was used, and it identified the brain under antibody attack. Ms. Widman stated her son had IVIG treatments. She stated her son currently is a junior at the University of Kansas studying computer science and has been employed.

Ms. Widman also shared her daughter's experience at nine years of age. After three winter illnesses, the child exhibited multiple physical symptoms and out-of-control spasms. Ms. Widman stated her daughter had eight hospitalizations in nine weeks at five different hospitals before the results of the Cunningham Panel test showed her daughter in the top three percent of the worst encephalitis cases. She also explained the brain injury caused by the immune system's attack left her daughter with the developmental level of an infant, having to again go through infant development, such as reaching, rolling, crawling, and eventually walking. Ms. Widman stated her daughter had various treatments, including IVIG. She stated her daughter is under the care of a neurologist in Seattle, Washington.

Ms. Widman concluded her testimony stating she is asking Kansas doctors receive education in neuro-immune illnesses and insurance companies pay for the treatments of these illnesses. She added catching and treating the illnesses early means the destruction from the illness will not spread, and there will be less damage to repair ([Attachment 17](#)).

Kai Widman, a private citizen who contracted autoimmune encephalomyelitis, offered testimony regarding his experience. He described his illness as his mind and body being locked, oscillating between non-function and dysfunction, and trying to explain what was happening, but the explanation was not understood by anyone. Mr. Widman described desperately waiting for the cerebral thunder to subside. Mr. Widman stated, as an encephalitis patient, he still deals with severe intermittent depression, bouts of intense suicidality, and occasional panic attacks. He attributed his success to his parents and their determination to find a doctor who could help him ([Attachment 18](#)).

Jerad Widman, MD, a family physician, offered his testimony to the Committee. He stated his hope for education for local doctors, effective treatments, and early diagnosis of autoimmune illnesses affecting the brain and central nervous system, as well as requiring insurance companies to pay for treatments. He stated the earlier the disease is identified, the better the long-term outcome and with less cost. Dr. Widman stated encephalitis illnesses are known as the rich person's illness because a family has to be rich to survive it. Dr. Widman described a 57-question survey about PANS/PANDAS and autoimmune encephalitis diseases, which asked families about the cost of the illness. The survey was done in 2018 by Moleculera Labs, who shared the results of the survey for this hearing as informational only because the survey results have not been published. Dr. Widman shared a summary statement from the survey that identified insurance covering only a portion of testing or treatments, leaving family with out-of-pocket costs for testing, treatment, and other associated costs running into the tens of thousands and sometimes hundreds of thousands of dollars. Parents have had to borrow, deplete retirement savings, or even declare bankruptcy. His testimony included a brief summary of unpublished data on the financial impact of PANS/PANDAS on families from the Moleculera Labs study and a list of categories of expenditures and losses for the families and categories of expenses to the State. Dr. Widman stated, for his family, medical bills for one year added up to \$1.1 million, not including anything paid out-of-pocket for alternative care, supplements, diet, travel, and other expenses. Over seven years, he estimated his family spent or lost a total of approximately \$700,000 for two children after insurance payments toward the expenses. He

provided a final example of a recent treatment that was 100 percent approved prior to treatment, but after the treatment the insurance carrier refused to pay, leaving the family with a \$47,000 medical bill ([Attachment 19](#)).

In response to a question, Dr. Widman stated had his children been correctly diagnosed earlier, they probably would not have suffered as much because, even with all the damage the illnesses caused, they still responded with treatments such as the IVIG.

The Chairperson thanked the conferees for their testimony.

## **Discussion of Policy Considerations**

Discussion ensued, with the following items discussed and requests made:

- A comment was made if the Legislature moved forward with any kind of insurance coverage mandates, it would be necessary to follow the cost-benefit analysis and then complete the test tracking.
- It was noted the Kansas Medical Society (KMS) determines the curriculum for medical doctors, as well as other professional groups.
- KLRD staff was asked to research information from other states who have mandated insurance coverage for these illnesses and provide it to the Committee members.
- KMS should be part of the discussion of the illness and the progression toward more intense treatments.

Eileen Ma, Office of Revisor of Statutes, noted, in the course of the cost-analysis study, the Kansas State Employees Health Care 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.

KLRD staff distributed the Chairperson's proposed language for the Committee report to the Committee members in the room and attending *via* Zoom ([Attachment 20](#)). The language was read and an additional statement was requested to be added to the proposed language. The additional language was stated as "and to direct this report be given to both the Senate Financial Institutions and Insurance and House Insurance Committees."

The proposed language is recommending a review of the insurance implications of such a mandate. Any request for an insurance payment mandate would be generated from the Legislature's insurance committees.

Ms. Ma clarified before a bill would be drafted, the cost-benefit analysis would be completed using the state employee health plan and then, with agreement to pursue a mandate, a bill could be drafted to mandate the coverage containing specific details on the treatment modalities covered. Any insurance mandates would not apply to self-insured plans, short-term limited duration plans, and the Farm Bureau plan authorized by legislation enacted in 2019 HB

2209. The State would not be able to mandate coverage for any plans that do not fall under the State's oversight.

Another request for a language change agreed to was replacing "the" with "any" in the last sentence, so it would read, "[t]he committee recommends that the 2021 Legislature review the insurance implications of any proposed payment mandate on both the public and private payer community."

KLRD staff provided the *2020 Kansas Legislator Briefing Book* article "Kansas Health Insurance Mandates," which included a list of coverage mandates ([Attachment 21](#)).

Additional documents for reference provided by KLRD staff included:

- Kansas State Employees Health Care Commission, "Report on Insurance Coverage for Autism Spectrum Disorder Pilot" ([Attachment 22](#));
- Kansas State Employees Health Care Commission, "Report on Insurance Coverage for Amino Acid Based Elemental Formula for Pilot" ([Attachment 23](#));
- 2010 Senate Sub. for HB 2160 ([Attachment 24](#)); and
- 2018 SB 348 ([Attachment 25](#)).

## Adjourn

With no further business, the Chairperson adjourned the Committee at 2:52 p.m.

Prepared by Sky Westerlund

Edited by Iraida Orr and Marisa Bayless

Approved by the Committee on:

January 7, 2021  
(Date)