

INTERIM JOINT COMMITTEE ON HEALTH, WELFARE, AND FAMILY SERVICES

Minutes of the 1st Meeting of the 2021 Interim

June 16, 2021

Call to Order and Roll Call

The 1st meeting of the Interim Joint Committee on Health, Welfare, and Family Services was held on Wednesday, June 16, 2021, at 1:00 PM, in Room 154 of the Capitol Annex. Senator Ralph Alvarado, Chair, called the meeting to order, and the secretary called the roll.

Present were:

Members: Senator Ralph Alvarado, Co-Chair; Representative Kimberly Poore Moser, Co-Chair; Senators Julie Raque Adams, Karen Berg, Danny Carroll, Denise Harper Angel, Jason Howell, Stephen Meredith, Michael J. Nemes, and Max Wise; Representatives Danny Bentley, Adam Bowling, Josh Bray, Tom Burch, Ryan Dotson, Daniel Elliott, Ken Fleming, Deanna Frazier, Mary Lou Marzian, Melinda Gibbons Prunty, Felicia Rabourn, Josie Raymond, Steve Riley, Scott Sharp, Steve Sheldon, Nancy Tate, Russell Webber, Susan Westrom, and Lisa Willner.

Guests: Dr. John Weeks, Norton Healthcare; Dr. Jeffrey M. Goldberg, State Legislative Chair, American College of Obstetricians and Gynecologists; Dr. Connie White, Deputy Commissioner, Department for Public Health, Cabinet for Health and Family Services; Kelly Joplin, MSW, Associate Professor, Carver School of Social Work, Campbellsville University, SEPPA Southeastern Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (Pandas)/Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) Association, Kentucky Committee Lead, PANS/PANDAS Parent; Dritan Agalliu, PhD, Principal Investigator, Department of Neurology; Columbia University Irving Medical Center; Michelle Liberatore, PANDAS Parent, Lobbyist, Advocate; Mark Kleiner, President, Preferred Insurance Group PANS/PANDAS Parent; Sarah Roof, Executive Director, Kentucky Hands and Voices; Sarah Streeval, Parent, Bella's Bill 4 CMV; Joseph Klausing, Chair, Kentucky Rare Disease Advisory Council; Sarah Vanover, Director, Andrea Day, Assistant Director, Division of Child Care, Department for Community Based Services, Cabinet for Health and Family Services; and Julie Brooks, Policy Specialist, Department for Public Health, Cabinet for Health and Family Services.

LRC Staff: DeeAnn Wenk, CSA, Chris Joffrion, Samir Nasir, Becky Lancaster, Hillary Abbott, and Amanda DuFour.

Consideration of Referred Administrative Regulations

The following referred administrative regulation with amendments were placed on the agenda for consideration: **201 KAR 002:380 Proposed** - Board authorized protocols; **201 KAR 002:410 Emergency** - Ordering and administering vaccinations; **201 KAR 008:505 Emergency** - Administration of COVID-19 immunizations; **201 KAR 020:065 Proposed** - Professional standards for prescribing Buprenorphine-Mono-Product or Buprenorphine-Combined-with-Naloxone by APRNs for medication assisted treatment for opioid use disorder; **201 KAR 020:370 Proposed** - Applications for licensure; **201 KAR 020:411 Proposed** - Sexual Assault Nurse Examiner Program standards and credential requirements; **201 KAR 020:660 Proposed** - Licensed certified professional midwives duty to report; **201 KAR 022:170 Proposed** - Physical Therapy Compact Commission; **201 KAR 023:070 Proposed** - Qualifying education and clinical practice experience under supervision; **201 KAR 023:150 Proposed** - Complaint procedure, disciplinary action, and reconsideration; **201 KAR 045:130 Proposed** - Continuing education; **900 KAR 006:030 Proposed** - Certificate of need expenditure minimums; **900 KAR 006:055 Proposed** - Certificate of need forms; **900 KAR 006:060 Proposed** - Timetable for submission of certificate of need applications; **900 KAR 006:065 Proposed** - Certificate of need application process; **900 KAR 006:080 Proposed** - Certificate of need emergency circumstances; **900 KAR 006:090 Proposed** - Certificate of need filing, hearing, and show cause hearing; **900 KAR 006:095 Proposed** - Certificate of need administrative escalations; **900 KAR 006:100 Proposed** - Certificate of need standards for implementation and biennial review; **900 KAR 006:105 Proposed** - Certificate of need advisory opinions; **900 KAR 006:110 Proposed** - Certificate of need notification requirements; **900 KAR 006:115 Proposed** - Certificate of need requirement for critical access hospitals, swing beds, and continuing care retirement communities; **900 KAR 011:011 Proposed** - Repeal of 900 KAR 011:010; **902 KAR 004:150 Emergency** - Enhanced HANDS services in response to declared national or state public health emergency; **902 KAR 010:010 Proposed** - Public restrooms; **902 KAR 010:110 Proposed** - Issuance of on-site sewage disposal system permits; **902 KAR 010:131 Proposed** - Repeal of 902 KAR 010:060 and 902 KAR 010:130; **902 KAR 010:140 Proposed** - On-site sewage disposal system installer certification program standards; **902 KAR 010:150 Proposed** - Domestic septage disposal site approval procedures; **902 KAR 010:160 Proposed** - Domestic septage disposal site operation; **902 KAR 010:170 Proposed** - Septic tank servicing; **902 KAR 020:160 Proposed** - Chemical dependency treatment services and facility specifications; **902 KAR 020:160 Emergency** - Chemical dependency treatment services and facility specifications; **902 KAR 020:440 Emergency** - Facilities specifications, operation and services; residential crisis stabilization units; **902 KAR 020:440 Proposed** - Facilities specifications, operation and services; residential crisis stabilization units; **902 KAR 030:210 Emergency** - Enhanced early intervention services in response to declared national or state public health emergency; **902 KAR 045:160 Proposed** - Kentucky food and cosmetic processing, packaging, storage, and distribution operations; **902 KAR 095:040 Proposed** - Radon Contractor Registration Program; **907**

KAR 007:020 Proposed - 1915(c) Home and community based services waiting list and waiting list placement appeal processes; **907 KAR 015:070 Emergency** - Coverage provisions and requirements regarding services provided by residential crisis stabilization units; **907 KAR 015:070 Proposed** - Coverage provisions and requirements regarding services provided by residential crisis stabilization units; **907 KAR 015:080 Emergency** - Coverage provisions and requirements regarding chemical dependency treatment center services; **907 KAR 015:080 Proposed** - Coverage provisions and requirements regarding chemical dependency treatment center services; **908 KAR 002:270 Proposed** - Community behavioral health training; **921 KAR 003:010 Proposed** - Definitions; **921 KAR 003:045 Proposed** - Issuance procedures; **922 KAR 001:490 Emergency** - Background checks for foster and adoptive parents and relative and fictive kin caregivers; **922 KAR 001:540 Proposed** - Registration of a foreign adoption; **922 KAR 001:580 Proposed** - Standards for children's advocacy centers; **922 KAR 002:120 Proposed** - Child-care center health and safety standards; **922 KAR 002:230 Proposed** - Director's credential; **922 KAR 002:240 Proposed** - Kentucky Early Care and Education Trainer's Credential and training approval; and **922 KAR 002:250 Proposed** - Commonwealth Child Care Credential. The administrative regulations above have been reviewed by the committee.

The following referred administrative regulation was placed on the agenda for consideration: **902 KAR 045:190 Proposed** - Hemp-derived cannabinoid products; packaging and labeling requirements. There was an agency amendment offered by the Kentucky Department for Public Health with the Cabinet for Health and Family Services. Julie Brooks, Regulations Coordinator, Department for Public Health, Cabinet for Health and Family Services, explained how the agency amendment would change the regulation. A motion to accept the agency amendment was made by Senator Adams and seconded by Representative Bowling. After a roll call vote of 25 yes votes, 0 no votes, and 2 pass votes, the agency amendment was accepted by the committee.

Legislative Hearing on the Child Care and Development Fund (CCDF) Block Grant Preliminary State Plan

Sarah Vanover, Director, and Andrea Day, Assistant Director, Division of Child Care, Department for Community Based Services, Cabinet for Health and Family Services, gave an overview of the 2022-2024 FFY CCDF Block Grant Preliminary State Plan. The block grant was reviewed by the committee.

Rare Disease Advisory Council Update

Joseph Klausning, Chair, Kentucky Rare Disease Advisory Council, provided a brief overview of the council and its membership. He is the newly appointed chair and the Governor has yet to appoint the rest of the members. He thanked the legislators for the passage of legislation that will help Kentuckians with rare diseases.

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) Syndrome and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS)

Representative Melinda Gibbons Prunty gave a brief overview of PANDAS and PANS coverage in other states and the steps taken regarding her request for a PANDAS and PANS task force. Dritan Agalliu, PhD, Principal Investigator, Department of Neurology, Columbia University Irving Medical Center, presented information on the genetic studies of PANDAS and PANS on humans and animals. The presence of the disease is often associated with streptococcal infection. Early treatment of the infection may prevent the disease from developing.

In response to questions from Representative Bentley, Dr. Agalliu stated that the M1 protein has been implicated in PANDAS and PANS.

In response to questions from Representative Sheldon, Dr. Agalliu stated that there is an outstanding issue with diagnosing PANDAS and PANS. He stated there was a previous test to recognize the disease but it has come in to question by some studies. He stated that Columbia University Irving Medical Center has a dedicated team to evaluate methods to diagnose children with this disease.

In response to questions from Senator Berg, Dr. Agalliu stated that there are many cases of children with a streptococcal infection who are not aware that they have the streptococcal infection. He stated that sometimes the treatment of the streptococcal infection can be difficult.

Michelle Liberatore, PANDAS Parent, Lobbyist, Advocate, testified about her experience when her then seven year old daughter started showing symptoms of her later diagnosed PANDAS syndrome and the following impact of the disease on her daughter. Kelly Joplin, MSW, Associate Professor, Carver School of Social Work, Campbellsville University, SEPPA Southeastern Pandas/Pans Association, Kentucky Committee Lead, PANDAS/PANS Parent, testified about her experience of how her son battled PANDAS/PANS for over 10 years. She gave information regarding: the number of children that may have PANDAS or PANS, other misdiagnosis that may be received, the significance of an early diagnosis, and the importance of promoting access to treatment. Mark Kleiner, President, Preferred Insurance Group, PANDAS/PANS Parent, testified in favor of creating a task force to educate more people on PANDAS/PANS. He described his son's experience before and after his son's PANDAS/PANS diagnosis.

In response to questions from Representative Marzian, Ms. Liberatore stated that the number of Intravenous Immunoglobulin (IVIG) treatments needed varies among patients. Dr. Agalliu testified regarding the guidelines for PANDAS or PANS treatments including IVIG approach. Mr. Kleiner testified to the costs of the IVIG and plasmapheresis, blood plasma replacement, treatments.

In response to questions from Representative Moser, Ms. Joplin stated that many pediatricians are compassionate but often want to pass a patient onto a mental health or other provider because PANDAS/PANS presents with psychiatric or orthopedic symptoms. Representative Gibbons Prunty stated she is open to the idea of creating a workgroup within the Rare Disease Advisory Council to study and advise on PANDAS and PANS issues.

In response to questions from Representative Sheldon, Mr. Kleiner stated that there is a medical code for the PANDAS/PANS diagnosis but insurance companies may not pay for PANDAS or PANS treatments.

In response to questions from Representative Westrom, Representative Gibbons Prunty stated that there is an informational sheet about PANDAS/PANS in the meeting materials online. Sen. Alvarado stated that there are 350 psychiatrists in Kentucky including approximately 59 child psychiatrists.

Perinatal Infant Mortality and Maternal Mortality

Dr. Jeffrey M. Goldberg, Legislative Advocacy Chair, Kentucky Section, American College of Obstetricians and Gynecologists, presented the following information to the committee: a brief introduction to the concept of maternal and perinatal infant mortality, an overview of the main causes and yearly rates of maternal and infant mortality in the United States, the reasoning for formal mortality reviews, a summary regarding the Kentucky Mortality Review Committee, and recommendations to improve maternal and perinatal infant outcomes.

Dr. John Weeks, Norton Healthcare, presented the following information to the committee: his maternal services background and experience in Kentucky, the impact of the opioid epidemic and substance use disorders on maternal and perinatal infant death rates, praise for the Kentucky Perinatal Quality Collaborative (KyPQC), and a recommendation to go beyond the perinatal period to make Kentucky a great place for children to grow and develop.

Dr. Connie White, Deputy Commissioner, Department for Public Health, Cabinet for Health and Family Services, provided the following information to the committee: preliminary data from the Maternal Mortality Review Committee regarding 2017 maternal deaths and the contributing factors, a view of Kentucky's rates of neonatal abstinence syndrome by area, an explanation of the coordination of various committees, and the members that work to prevent maternal and perinatal infant deaths.

Kentucky Perinatal Quality Collaborative (KyPQC)

Dr. White presented an overview of the KyPQC goals, location, and membership. She reviewed Kentucky's status as an Alliance for Innovation on Maternal Health (AIM)

state and what tools and partnerships will help improve maternal and perinatal infant health.

Update on 2021 Regular Session House Bill 212

Dr. White presented the following information to the committee: a brief review of the bill, the information gathered regarding child and maternal fatalities, and how the information will be reported.

In response to questions from Senator Adams, Dr. White stated that in regards to 2018 Regular Session Senate Bill 250, the DPH is in the instructional phase which is to have healthcare providers test pregnant women for Hepatitis C. Dr. Weeks stated that private providers at Norton Healthcare were testing pregnant patients for Hepatitis C prior to the bill.

In response to questions from Representative Burch, Dr. Goldberg stated that the United States healthcare system spends more per capita than any other western country and at the same time it has worse health outcomes. He stated that there is a deficit in the healthcare system by not having the right technology supplied to the correct areas and patients in a systematic fashion.

In response to questions from Representative Willner, Dr. Weeks stated that there is a growing awareness of the under treatment of postpartum depression. The Kentucky Perinatal Association is reviewing data and information that primary care physicians can use to screen for depression and initiate care for the patient. The mortality review committee has identified suicide as a reason for some maternal deaths. The KyPQC will address mood disorders during pregnancy. The KyPQC is in the process of developing a maternal mortality review subcommittee to analyze what recommendations could have kept a patient from dying. Such data would allow the KyPQC to examine the efficacy of preventative programs.

In response to questions from Representative Marzian, Dr. White stated that she does not have the number of women not receiving prenatal care but she can send it to her. Dr. Weeks stated that the majority of infant deaths occur after the delivery.

In response to questions from Representative Moser, Dr. White stated that the maternal care for substance use disorder bundle is not implemented. DPH will be meeting with AIM representatives to begin pilot projects with evidence-based interventions that can be sent to hospitals to utilize.

In response to questions from Senator Berg, Dr. Weeks stated that it can be hard to confirm how often domestic abuse during pregnancy impacts maternal and perinatal infant deaths because many abused women do not admit to being abused. He stated that it is well

known that women who suffer from domestic abuse are more likely to die or be killed during the pregnancy.

Presentation on Cytomegalovirus (CMV) in Newborns

Sarah Streeval, Parent, Bella's Bill 4 CMV, testified about the following information: her daughter Bella's life and experience battling CMV, her goals to educate people and to advocate for other CMV families, the costs to care for Bella, and she shared brief stories about other children diagnosed with CMV.

In response to Senator Wise, Ms. Roof stated that CMV is not included in state mandated universal screenings for newborns but some states are doing targeted screening of newborns based on potential risk for the disease.

In response to Representative Moser, Ms. Roof stated that there may not be an exact cost of universal screening but it could be costly. She stated that in the long-term view, universal testing would be considered cost-saving or cost-neutral. Ms. Streeval stated that there are three different ways to test for CMV and that if a test is positive there is follow-up testing. Ms. Streeval stated that there is not a CMV prenatal test for an infant but there is a CMV test for the mother. Dr. Goldberg stated that a patient can be tested for CMV infection through a cervical swab but there is no data supporting that testing for all pregnancies. He stated there is no current antiviral treatment for CMV.

In response to Representative Bentley, Ms. Roof stated that there is a high percentage of people who have CMV in their lifetime but when pregnant women pass it on to a newborn child there can be serious effects from the virus. In many people CMV will present as a common cold. Sen. Alvarado stated that in a child's first four to five months of life they are completely dependent on maternal antibodies received from the birth mother to fight infections. Immunity problems, may not be recognized until the child is four to five months old and already impacted by CMV.

In response to Representative Berg, Ms. Streeval stated that if antivirals are given to newborns with CMV at birth, the development of hearing or vision loss may be prevented or slowed. She stated that mothers need to be educated regarding CMV and preventative measures. Ms. Roof stated that some children are asymptomatic at birth but test positive for CMV. She stated that there are developmental delays and additional costs when there is not an early diagnosis.

Adjournment

There being no further business, the meeting was adjourned at 3:25 PM.