

MINUTES**ARKANSAS PANS/PANDAS ADVISORY COUNCIL****Thursday, October 29, 2020****1:00 PM****Room A, MAC****Little Rock, Arkansas**

Advisory Council members present: Senator Kim Hammer, Co-Chair; Representative Les Warren, Co-Chair; Natalie Bradford, Matt Brumley, Ashley Collins, Kelea Duke, Cathy Puckett, Deborah Rice, and John Vinson

Senator Hammer called the meeting to order.

Consideration to Approve June 11, 2020 Meeting Minutes [EXHIBIT C]

Mr. Vinson made a motion to approve the June 11, 2020, Minutes, and with a second by Representative Warren, the motion carried.

Update—G. Richard Smith, M.D. Director, Psychiatric Research Institute (PRI), University of Arkansas for Medical Sciences (UAMS)

G. Richard Smith, M.D., Director, PRI, UAMS, gave an update on the Childhood Post-Infectious Autoimmune Encephalopathy (CPAE) Clinic at UAMS and Arkansas Children's Hospital (ACH). The clinic meets twice a month in the Child Study Center on the ACH campus. Dr. Aravindhan Veerapandiyan and Dr. Veronica Raney (medical directors) have worked out the previous flow issues and patients are now seen in a timelier manner. The Clinic is still in need of a full-time nurse, but the position was not included in the budget. They are currently operating with a nurse on loan from UAMS. Dr. Smith said that getting information uniformly to three thousand doctors is a challenge but they will redouble their efforts to get information to the appropriate people. Mr. Brumley referred to discussion from a previous meeting regarding a child's need for a primary care provider (PCP), to help with treatment, provide information, and assist with pretesting. UAMS has agreed to develop an informational flyer which will also be available for adult patients.

Discussion of Pace Foundation's Role with the CPAE Clinic, Arizona Medicaid, and PANS Global IVIG Clinical Trials Study

Mr. Paul Ryan, Co-Founder & President, PACE, spoke on the list of things to look and test for when suspecting PANS/ PANDAS. The information will be provided to ACH to post on their website to help better educate pediatricians. He stated that Arizona clinics have evolved to a full-time staff, funded by its medical provider Banner Health Network. Typically, 85% of the patients are analyzed at an early stage of the disease then returned to the PCP with prescriptions for antibiotics and steroids. The other 15% of patients are older children whose conditions have developed into serious cases. The future goal is to eliminate the clinics and give the PCP the ability to treat this disease early. The primary focus of the clinic is to return the child to the PCP with a plan of action for supervising the child's treatment with a defined course of action. Arkansas needs to develop an integrated system that can evolve through Dr. Veerapandiyan and Dr. Raney and allow them to build relationships within the community. This would also allow pediatricians to consult with them as needed.

Discussion Regarding Educational and Awareness Platform

Mr. Jason Miller, Plan President, Summit Community Care, noted in past programs submitted to the state, Summit Community Care has requested to use funds for community investment. A proposal has been submitted with an initiative to launch a training platform for use by providers and members across the state, and is expected to be approved this week. As the plan rolls out, teaching and training will be available at no cost to providers. This is not mandated but can serve as a PANS/PANDA training course for teachers, nurses, and physicians across the state. Mr. Ryan suggested that Mr. Miller coordinate with the Arkansas CPAE clinic in order to integrate the current and full path of available treatment. The modules should be vetted through Dr. Smith and his staff at their clinic.

Discussion of Arizona Medicaid (Handouts 1 & 2)

Mr. Ryan provided an overview of the background and current status of how Medicaid is handling the reimbursement of treatment associated with PANS. A letter of medical necessity was drafted with the co-directors of the Center and the Medicaid Care Management Organizations (CMO). The letter is then submitted on an expedited basis, along with a request for IVIG, which legally gives insurance companies 72-hours to respond. Medicaid officials were concerned and noted shortages of IVIG and over-prescription. The Arizona Center offered its services to give a second opinion about cases in which the Department of Human Services (DHS) suspected there was over-prescription; IVIG is applied to less than 10% of its children--the national average is 20%; the insurance acceptance rate is 95%. The University of Arizona has developed pre and post-tests of IVIG. Mr. Ryan also mentioned the legislation written in New Hampshire and said that he is in favor of proving the treatment is effective through evidence and medicine and by way of agreement, not necessarily by law.

Dr. William Golden, Medical Director, Division of Medical Services, DHS, stated that he advises staff of the effective use of resources and appropriate care for the population served. He noted consideration of the following:

- multiple ways of treating the disease
- condition is underdiagnosed/over diagnosed
- identify a patient for the right treatment
- literature on IVIG is mixed (Humana, Sandeen, and other companies)
- importance of diagnosis and documentation of the condition
- importance of clinical studies to look at different therapies
- identify where the patient is within the spectrum of the disorder
- identify the different therapies that would benefit the patient
- weakness of clinical evidence
- coverage decisions by major national insurers

Dr. Golden said he believes the best approach would be going through the CPAE Clinic assessment with a targeted approach and having the Center of Excellence consider the treatment.

Ms. Janet Mann, Director, Division of Medical Services, DHS, added that Dr. Golden handles every review on a case-by-case basis, and there have been cases diagnosed and approved for IVIG to be administered. She asked Dr. Smith to implement the letter of medical necessity here in Arkansas. Arkansas Medicaid requires a medical necessity component for the case to be considered.

Mr. Ryan suggested a trial program whereby the PCP determines a patient's need for IVIG; the patient goes to the CPAE Clinic for validation that the case is the proper last resort of treatment for the child, and the combined validation by the physician is tracked. The patient entering the study receives some application of IVIG that is monitored. If double validation is needed, the state may be able to reach an agreement with Arizona to review some of the cases.

Mr. Ryan provided details of the study's development and noted it is a phase 3 study, and if successful, IVIG will be immediately approved by the FDA. The budget for the study is \$30 million and will start the first quarter of 2021, at which time 92 children will be recruited.

Mr. Ryan has asked the Arizona legislature for \$250,000 as an investment in the area of research. He suggested Arkansas ask for 1) a starter kit of \$100,000 to open clinics, and 2) a research grant the first year for items such as Magnetic Resonance Imaging (MRI) brain scans.

With no further business, the meeting adjourned at 3:20 p.m.