

**MINUTES
ARKANSAS PANS PANDAS ADVISORY COUNCIL
MAC Room A
Little Rock, Arkansas
Thursday, June 11, 2020
3:30 PM**

The Arkansas PANS PANDAS Advisory Council met at 3:30 p.m. Thursday, June 11, 2020, in the Multi-Agency Complex (MAC), Room A, in Little Rock, Arkansas.

Advisory Council members present: Senator Kim Hammer, Co-Chairman, and Representative Joe Cloud, Vice Chairman, Chantel Allbritton (via teleconference), Natalie Bradford (via teleconference), Matt Brumley (via remote audio), Pasley Butler, Ashley Collins, Cathy Puckett, Deborah Rice, and Gregory B. Sharp, M.D.

Senator Hammer called the meeting to order.

CONSIDERATION TO APPROVE MARCH 9, 2020, MEETING MINUTES [EXHIBIT C]

Dr. Sharp made a motion to approve the March 9, 2020, meeting minutes, and with a second by Ms. Rice, the motion carried.

UPDATE—G. RICHARD SMITH, M.D. DIRECTOR, PSYCHIATRIC RESEARCH INSTITUTE (PRI), UNIVERSITY OF ARKANSAS FOR MEDICAL SCIENCES (UAMS) [HANDOUT 2]

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). He noted progress is slowed because of COVID-19. Some children have been seen, but not in the multidisciplinary fashion. He noted each child needs a primary care provider (PCP) to help with treatment, provide information, and assist with pre-testing. The clinic will assist families in finding a PCP if needed. The handout outlines what parents, referral sources, and children can expect, and it contains a permanent email address, fax number, and phone number with voice mail to be answered within 24 hours.

Dr. Smith noted ACH may stop seeing children 18 to 21 years old; but he assured members and Ms. Puckett that her 23 year old adult child and others with PANS could be seen at the PRI at UAMS. UAMS will develop a flyer for adults also and make it available.

Dr. Smith stated a part-time nurse was temporarily moved from UAMS to the CPAE Clinic at ACH and added the clinic needs a full-time nurse.

He noted a clinical trial by Octapharma is expected to open to the PACE network of clinics after final Food and Drug Administration approval. Dr. Smith explained the cost is covered by the pharmaceutical company.

Dr. Smith stated a nurse is needed to have an efficient clinic; an efficient clinic is needed to have enough patients for participation in the clinical trial. There are a series of things dependent upon the nurse. Dr. Sharp pointed out there would be two nurses involved; the clinical nurse who organizes the clinic and an ACH Research Institute clinical research nurse to run the clinical trial.

Dr. Smith noted the CPAE Clinic will operate one half-day per month, but as there are more referrals, hours will be extended. He stated the powerhouse of the clinical trial is Octapharma, and the PACE Foundation. UAMS is one of eight PACE clinics, and Mr. Ryan (of the PACE Foundation) does not anticipate trouble qualifying to be a study site. Dr. Sharp added when pharmaceutical companies sponsor trials and are selecting sites, the criteria is more about the clinic type and number of its patients that could be rolled into the study. A clinic nurse is needed to process incoming referrals and expand the pool from which Arkansas CPAE patients would be selected to be participants in the clinical trial.

Dr. Smith concluded by noting members of UAMS on the Interdisciplinary Panel are Dr. Veerapandiyam, Dr. Raney, and himself. Senator Hammer added the other members are Natalie Bradford, Matt Brumley, and Dr. Michael R. Martin. Ms. Leslie Fisk from UAMS is the point person for the Interdisciplinary Panel and will facilitate future Panel meetings.

INSURANCE COVERAGE DISCUSSION

Ms. Paula Stone, Deputy Director, Division of Medical Services, Department of Human Services (DHS), noted Medicaid treats the diagnosis that is primary to a treatment; a PANDA diagnosis is usually secondary. The reimbursement rate for intravenous immune globulin (IVIG) changes daily.

Ms. Janet Mann, Director, Division of Medical Services, DHS, stated Medicaid views this issue as paying for the components of CPAE, it does not have a program by which it treats all the symptoms as one. Medicaid divides reimbursement across treatment of behavioral health symptoms, treatment provided by a PCP, and pharmacy services. Medicaid offers a program to its beneficiaries by which there is care coordination for specific types of beneficiaries that have specific issues. There is not a specific care coordination for CPAE offered, but Medicaid has a patient-centered medical home (PCMH) that has a case management care coordination component. Services can be coordinated for Medicaid beneficiaries.

Medicaid beneficiaries with behavioral health symptomology that have received a qualifying behavioral health diagnosis combined with a functional deficit (unable to function in home and community settings), may go into a Provider-led Arkansas Shared Savings Entity (PASSE) program, which has a large care coordination component. Care coordination and coordination of all the different components of services may be coordinated for a PASSE member. The PASSE program would reimburse for the same components that Medicaid reimburses; behavioral health treatment, treatment by a PCP, and pharmacy services. There is not a bundled rate for this.

Ms. Rice gave testimony of how her child changed overnight and worsened to the point that he was put into a psychiatric facility at the age of eight. She was told her child was the most suicidal the facility had seen but did not know why. He was given antibiotics and improved somewhat and IVIG was ordered as a non-traditional method. He is on Medicaid and Ms. Rice learned reimbursement was \$140 for the \$9,000 treatment and no hospital would take that. The family continued without IVIG and was back in the psychiatric facility within two weeks. Although her family is able to self-pay, she asked DHS what are families to do that cannot afford this drug?

Dr. Sharp indicated he has used IVIG for auto-immune disorders and can clearly see a dramatic response in the child. A conflict of information exists but there are two things this clinic will help with. First, in today's exhibits, the primary indications for IVIG use are in moderate to severe cases. This will limit use to those who really need it with regard to the protocol which calls for antibiotics first, anti-inflammatories, corticosteroids, and then IVIG. Second, results of the anticipated trial will give scientific evidence that would support payment by Medicaid and other insurance companies. To clarify, the standard cost of IVIG is \$100 per gram, and the ratio is typically 1.5 to 2 grams per kilogram of body weight, therefore the dose for a 44 pound child would cost about \$4,000. Ms. Bradford asked what about those who need insurance reimbursement now?

Dr. Smith noted he has talked with Paul Ryan of the PACE Foundation recently and Medicaid in Arizona will pay full cost of treatment for its CPAE patients. Arkansas and Arizona clinics have the same protocol and Mr. Ryan said Arizona Medicaid Director had offered to call Medicaid authorities in other states about its approach. If that could be set up, it would be helpful to Ms. Mann.

Senator Hammer asked Ms. Mann to let him know when she has talked with Arizona's Medicaid Director, so she could be included on the PANS PANDAS agenda to discuss her conversation.

Ms. Maxine Greenwood, Director, Government and Media Relations, Arkansas Blue Cross Blue Shield (BCBS) (remote audio), introduced Dr. Martin to give an overview of clinical involvement and participation to date.

Dr. Michael Martin, Medical Director, BCBS (remote audio), noted he was in contact with Dr. Smith earlier in the year and the process and protocol will be taken to BCBS Policy Committee, but the clinical trial's outcome will determine a definitive change in policy. BCBS is willing to work with Dr. Smith and Dr. Sharp to generate a pilot policy specific to ACH and UAMS.

Dr. Martin explained cases where IVIG was approved, there have been no complaints about BCBS' level of reimbursement. The appeal process for denial of PCP-ordered IVIG treatment has different levels. The Patient Protection and Affordable Care Act would appeal to the Arkansas Insurance Department, which may require external or independent review. A self-insured group would call the insurance payer which would decide whether or not to overturn an appeal.

Ms. Bradford noted she is seeing a patient that BCBS denied IVIG treatment and the reason given was 'no supporting laboratory data to support diagnosis.' She noted the patient has a diagnosis of ICD-10 codes G93.49 and Z89.89. Dr. Martin stated BCBS does not cover it, and as yet does not recognize the IVIG treatment benefit to patients. The codes mentioned are non-specific and require medical records to ascertain the exact diagnosis, and the BCBS-recognized indications for IVIG. Senator Hammer wants Ms. Bradford and Dr. Martin to confer off line and spotlight this case for the committee.

Rep. Cloud asked Dr. Martin for a specific ICD-10 code for PANDAS, and for BCBS to furnish the committee the total number of requests that have been denied for IVIG due to PANDAS syndrome. Dr. Martin noted there is a specific ICD-10 code for PANDAS in the ICD-10 2020 Manual.

Ms. Rice asked to include in the request of information from insurance companies the under covered, such as \$140 reimbursement for treatment costing thousands. Senator Hammer said it would include, if paid, what was the amount paid.

Ms. Greenwood stated BCBS would compile and submit the requested information.

Mr. Jack Hopkins, Manager and Government Relations Operations, Arkansas Total Care and Qual Choice, noted 30 PA requests for IVIG through Ambetter Market Place Plans with no denials; none were tied to PANS PANDAS. Total Care has not received requests for IVIG, but he will find out about Qual Choice and will follow-up with the committee regarding reimbursement rates.

Mr. Jason Miller, Chief Executive Officer, Summit Community Care, noted Summit Community Care has no cases related to PANS PANDAS but has processes and policies in place that pay for IVIG.

Mr. Robert Slattery, Chief Executive Officer, Empower Healthcare Solutions, stated Empower will provide the information to the committee, but he did not have it today.

Senator Hammer stated the committee is looking for reimbursement patterns for PANS PANDAS, and the diagnosis under which IVIG treatment was paid. He asked the PASSE group to return for the next meeting with this information.

Senator Hammer requested on behalf of the committee that the 5% PASSE can utilize for community services, be paid to help offset the cost to hire and train a nurse for the CPAE clinic. He asked the PASSE group to look at working together as a team of three, along with any other carriers that want to join in, to champion this cause as part of their community investment, and put their money together for that. He asked the PASSE group if this is a consideration, to let him know as soon as possible. The PASSE group each noted interest in participating noting it would need review by their respective internal Committees for Community Investment, and agreed to get back to the committee.

MEDICAL RESEARCH REPORTS-INFORMATION [EXHIBITS F1, F2, F3, F4]

Senator Hammer called attention to Exhibits F1 through F4, reports provided by Ms. Bradford, and asked that members read and be familiar with them.

DISCUSSION ON SECURING FUNDING

[EXHIBIT G]

Senator Hammer noted, Exhibit G a draft letter from the committee to the governor to ask for \$175,000 out of the Rainy Day Fund to help secure a nurse for the CPAE clinic. He will have Senator Irvin and Representative Cloud's names added to the draft, if they are agreeable. The support letter from UAMS will be included

Rep. Cloud made a motion to approve sending the letter to the governor. Ms. Puckett noted the adult population needed to be included in the language.

Senator Hammer stated to add language in the second paragraph to say, "This is to include treatment of the adult population."

Rep. Cloud then amended his motion to approve the Exhibit G draft letter, with an additional sentence in the second paragraph reading "This is to include treatment of the adult population.", and to send the letter to the governor. With a second by Ms. Puckett, the motion carried.

OTHER BUSINESS

[HANDOUT 1]

With no further business, the meeting adjourned at 5:16 p.m.