

**MINUTES
ARKANSAS PANS PANDAS ADVISORY COUNCIL
MAC Room B
Little Rock, Arkansas
Monday, March 9, 2020
3:30 PM**

The Arkansas PANS PANDAS Advisory Council met at 3:30 p.m. Monday, March 9, 2020, in the Multi-Agency Complex (MAC), Room B, in Little Rock, Arkansas.

Advisory Council members present: Senator Kim Hammer, Co-Chairman, and Representative Les Warren, Co-Chairman; Representative Joe Cloud, Vice Chairman, Chantel Allbritton, Natalie Bradford, Matt Brumley, Pasley Butler, Ashley Collins, Kelea Duke, Deborah Rice, Gregory B. Sharp, M.D., Sue Tedford, and John Vinson.

Senator Hammer called the meeting to order and clarified the legislation that uses the words “Interdisciplinary Panel” in one part and “Interdisciplinary Team” in the other part. They are both one and the same. Moving forward it will be referred to as the “Interdisciplinary Panel”.

CONSIDERATION TO APPROVE JANUARY 2, 2020, MEETING MINUTES [EXHIBIT C]

Representative Cloud made a motion to approve the January 2, 2020, meeting minutes, and with a second by Representative Warren, the motion carried.

INTERDISCIPLINARY PANEL/TEAM REPORT

[HANDOUT 1]

G. Richard Smith, M.D., University of Arkansas for Medical Sciences (UAMS), noted the Interdisciplinary Panel met Friday, March 6, 2020, on a conference call. The clinic will be located in the Neuro-Science Center at Arkansas Children’s Hospital (ACH).

Veronica Raney, M.D., Child Study Center, UAMS, discussed the handout noting the following:

- Childhood Post-Infectious Autoimmune Encephalopathy (CPAE) Clinic
- Clinic’s aim and diagnostic criteria for PANS
- Differentials–list of things other than PANS that might be going on
- Pre-appointment lab requirement information (provided by Arizona CPAE Clinic)
- Clinic process, highlighting the importance of the different parts of the assessment
- A unique phone number for clinic referrals (number becomes active March 10)

Dr. Smith noted there are 10 or so cases that need to be worked up. Currently part-time nurses are needed for medical record review and family support, but a full time clinical nurse to support Dr. Raney and Dr. Veerapandian is needed. A potential CPAE nurse has been identified and UAMS is talking with her about the position.

Ms. Rice asked if there is a member at large who is a medical director or medical officer from an insurance company licensed in this state to assist in the development of diagnostic criteria for future insurance coverage purposes on the Interdisciplinary Panel.

Senator Hammer noted the Interdisciplinary Panel members include Dr. Smith, Dr. Raney, Dr. Veerapandian, Natalie Bradford, and Matt Brumley.

Dr. Smith said he has had conversations with Dr. M.R. Martin, Policy Medical Director, Arkansas Blue Cross Blue Shield, and plans to meet with him to go over protocol. Senator Hammer responded that's who it is, and who will be at the next committee meeting.

Mr. Brumley noted the Council's mission is to get insurance companies to have a reasonable reimbursement for treatment and diagnosis of PANS PANDAS. His concern is for children who age-out of coverage for CPAE. He understands the scope of care is to be broadened and thinks the Council should prepare and not have to revisit this issue due to having to recode for children versus adults. Dr. Smith said they have the capacity to see adult patients.

Representative Warren asked if there are codes for PANS PANDAS to get reimbursements or is that another obstacle to get the Insurance Department involved where you are trying to treat someone and not getting reimbursed.

Dr. Smith noted there are two issues: 1) Is there a code; and 2) Can you get reimbursement. He said he spent time looking for the codes and could not find them, although he has not yet had a billing expert help with this. He said when they begin working collectively with the payors, i.e. Blue Cross Blue Shield, Medicaid, and Medicare, they will tell the providers which codes are for them.

Senator Hammer noted there must be a code in order to bill the insurance company for reimbursement.

Ms. Bradford said the codes she currently uses to cover lab work are: D89.89-other encephalopathy, and G93.49-other autoimmune unspecified.

Dr. Smith wants discussions with payors such as insurance companies, Medicaid, and Provider-led Arkansas Shared Savings Entities (PASSEs) in order to receive an agreement from them regarding coverage. Senator Hammer noted these entities will be on the next meeting's agenda

Dr. Smith reported to the committee that the Interdisciplinary Panel is networked with the PACE Foundation and Dr. Raney and Dr. Veerapandian recently went to Tucson, Arizona to meet with the consortium consisting of University of Arizona, UCLA, Stanford, Wisconsin, and people there from Massachusetts General. There will be a couple more on the east coast and maybe one at Emory. Arkansas will be a regional referral hub for that network.

PANS PANDAS CLINIC

Dr. Smith noted UAMS staffs all the physicians for ACH, so Dr. Raney and Dr. Aravindhan Veerapandian will see the patients. The nurse will be employed by UAMS and will work at the CPAE Clinic on the ACH campus. The position requires a full time nurse per one half to one whole day of clinic per week for pre-work.

Dr. Raney added there is a triage process set up with a clinical provider deciding whether the patient should go through therapy or the medical clinic first. The therapist or medical doctor will decide if the patient needs to be seen on both sides of the clinic. She stated the goal is to hire a nurse dedicated to be the nurse coordinator for the CPAE Clinic.

Dr. Sharp noted this is a very specific clinic and will be in the Neuro Science Clinic at ACH and will only receive PANS PANDAS referrals.

Dr. Raney noted the system requires heavy involvement of the CPAE nurse coordinator. The call comes to the CPAE nurse who collects a large volume of information then confers with the doctors who decide what lab work is to be done prior to intake. Decisions can be made more quickly following the physical exam and interview if lab work is already done. This is what has been done in Arizona. If the Primary Care Physician (PCP) refuses to allow lab work prior to the physical exam and interview, it will delay the diagnosis. Recently, Arizona modified its process by hiring an APRN to do the first visit and order labs, then on the second visit the patient sees the doctors. All the different information must be put together using medical knowledge to make a discerning decision.

Dr. Sharp added changes could be made in order to have all the information, including lab work, before a patient sees the doctor so the visit is as efficient as possible. Once the patient is in the system, orders for labs could be done at ACH prior to a clinic visit.

ARKANSAS CHILDREN'S HOSPITAL/UNIVERSITY OF ARKANSAS FOR MEDICAL SCIENCES \$175,000 FUNDING REQUEST PRESENTATION AND JUSTIFICATION [HANDOUT 2]

Dr. Smith said the clinic needs to get funds flowing, and UAMS has agreed to front the money to get the clinic going. Money to hire a full time nurse will allow smoother transition instead of the "starts and stops" the clinic has had up to this point by using part-time nurses. The funding request also includes physician education/academic detailing which includes confirming PANS PANDAS as a diagnosed illness, its symptoms, and signs to look for.

Dr. Smith noted he has worked for nine months to get \$175,000 from UAMS freed up and not been able to do it. He has composed a letter on behalf of UAMS requesting assistance of \$175,000 from the governor in hopes of getting the money more quickly. \$100,000 will be used for a nurse's position and \$75,000 for education. He explained:

- \$60,000-\$70,000 salary for a highly trained nurse with significant medical experience and \$30,000-\$40,000 for UAMS benefits. The position has not yet been posted.
- \$75,000 for physician education and will not be used to see patients.

Representative Cloud made a motion to express agreement with the request and to add the Advisory Council members' names to the official request to the governor to ask for this money. Mr. Brumley seconded the motion, and the motion carried.

SUBCOMMITTEES' MEMBERSHIPS AND RESPONSIBILITIES

[EXHIBIT G]

Senator Hammer suggested Representative Warren chair Subcommittee #1 and Representative Cloud chair Subcommittee #2 and to start coordinating meetings through Ms. Stapleton, possibly using conference calls.

OTHER BUSINESS

Dr. Smith mentioned the Ryan's, from the PACE Foundation, plan to be present for the clinic's grand opening. There will be many schedules to consider for this. With no further business, the meeting adjourned at 4:31 p.m.