

MINUTES

ARKANSAS PANS/PANDAS ADVISORY COUNCIL

Friday, December 4, 2020

1:00 PM

Room A, MAC

Little Rock, Arkansas

Advisory Council members present: Senator Kim Hammer, Co-Chair; Representatives Les Warren, Co-Chair; Joe Cloud, Vice Chair; Chantel Allbritton, Natalie Bradford, Matt Brumley, Pasley Butler, Ashley Collins, Cathy Puckett, Deborah Rice, Dr. Gregory Sharp, and Sue Tedford

Senator Hammer called the meeting to order.

Consideration to Approve October 29, 2020 Meeting Minutes [Exhibit C]

Representative Cloud made a motion to approve the October 29, 2020, Minutes, and with a second by Ms. Puckett, the motion carried.

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

G. Richard Smith, M.D., Director, PRI, UAMS, provided an update on the Childhood Post-Infectious Autoimmune Encephalopathy (CPAE) Clinic at UAMS and Arkansas Children's Hospital (ACH). He noted the clinic meets twice a month and continues to operate smoothly. Due to generous donations, the clinic has secured funding to hire a nurse for one year; once the nurse has been hired, one clinic per week will be allowed to operate, resulting in additional referrals. The nurse will work both the pediatric and adult clinics and facilitate blood work from the primary care provider in advance of a visit to the clinics.

An updated informational flyer describing the services offered to adult patients at UAMS was presented to task force members. Beginning next week, web-based material from the University of Arizona will be transferred to the University of Arkansas website for their CPAE Clinic and to the Arkansas Department of Health. The information will soon be available online.

Ms. Bradford made a motion that pending a consultation and common agreement between Representative Cloud and Dr. Smith, along with committee approval, the adult and pediatric flyers may be disbursed to the public. With a second by Ms. Puckett, the motion carried.

Update – Mr. Paul Ryan, Co-Founder and President, PACE Foundation

Mr. Paul Ryan, Co-Founder & President, PACE Foundation, spoke on the nursing position made available by anonymous donors from Arizona and Arkansas. He anticipates the position will be filled rapidly at which time clinic scheduling will change from twice per month to a regularly scheduled weekly clinic.

The universities will host a conference for doctors to share forums and major breakthroughs, such as tracking IVIGs and insurance company proofs based on performance. Medicaid manuals define experimental treatments in general. It was noted that Arizona's clinics are not experimental but a

standard of care. He encouraged Arkansas's efforts for a legal remedy or to push the idea for trial. The third entity of these efforts will be the IVIG trial, which will take one to two years to publish.

Mr. Ryan said the difference between a clinic and a center is that a clinic does not have the capacity for teaching and research. He suggested that Arkansas change its name to reflect the Center of Excellence recognition. He noted a Center of Excellence has three elements:

- Teaching about the disease or disorder
- Research through participation
- Diagnosing and treating patients

Mark White, Chief of Staff and Chief of Legislative Affairs, Department of Human Services (DHS), stated that DHS would look at the CPAE Clinic as not being experimental in light of Medicaid guidelines requiring treatment to be medically necessary for the individual. He said sample or randomized trials typically cannot be paid for by Medicaid unless there is a waiver from the Federal Centers for Medicaid and Medicare Services (CMS). Medicaid service must be available for anyone who medically qualifies for it.

There are criteria that apply across all cases but are a determination that depends on an individual's condition, diagnosis, and situation.

Senator Hammer requested Representative Cloud and Natalie Bradford work with Medicaid to find a pathway forward regarding a clinical trial or to take on the challenge of the term "experimental" utilizing Arizona's work.

Dr. Sharp added there are three considerations for clinical trials: 1) consideration of standard of care; 2) higher level of evidence based medicine; and 3) agreed upon treatment indication. Double-blind placebo-controlled trials are going to be the gold standard in order for PANS/PANDAS to be universally accepted.

Discussion of Arkansas Children's Hospital PANS/PANDAS Clinic

Dr. Rick Barr, Executive Vice President/Chief Clinical and Academic Officer, ACH, gave an overview of ACH's role regarding the CPAE Clinic.

Future Legislation [Exhibit G]

Senator Hammer stated the involvement of the PACE Foundation has made the committee's work easier but due to COVID-19 restrictions, plans to sunset by the end of the year have changed. Representative Warren proposed the committee continue in its capacity and he referred to the proposed legislation (Exhibit G). He gave an overview of the appropriation request to UAMS for the nursing position. **(Handout 1)**

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