

## MINUTES

### ARKANSAS PANS/PANDAS ADVISORY COUNCIL

Thursday, October 6, 2022

10:00 AM

Room B, MAC

Little Rock, Arkansas

Advisory Council members present: Senators Kim Hammer, Chair; and Missy Irvin; Representatives Les Warren, Vice Chair; and Joe Cloud; Matt Brumley, Dan Honey, Cathy Puckett, Sue Tedford, and Joel Tumblison

Other members present: Representative Johnny Rye

Senator Hammer called the meeting to order.

#### **Consideration to Approve the May 23, 2022, Meeting Minutes [Exhibit B]**

Matt Brumley made a motion to approve the minutes, seconded by Cathy Puckett, and the motion carried.

#### **Update on Pharmaceutical Trials and Discussion of Pathway Forward for PANS/PANDAS Treatment**

Paul Ryan, Co-Founder and President, PACE Foundation gave an update on the FDA check on IVIG trial centers in the United States. Universities around the country in the phase three trial on the drug IVIG passed and the trial has been expanded to Europe. There is a need for more children to enter the trial for the success of IVIG.

#### **Discussion of Guidelines for Primary Care Physician Treatment of PANS/PANDAS at the University of Arkansas Medical Sciences (UAMS) [Handouts 1, 2, and 3]**

Mr. Ryan, and Dr. Aravindhan Veerapandiyan, Co-Medical Director UAMS Childhood Post-Infectious Autoimmune Encephalopathy (CPAE) Clinic, Director Arkansas Children's Hospital (ACH) Comprehensive Neuromuscular Program, Medical Director ACH Headache Clinic, Assistant Professor UAMS Pediatric Neurology, and Dr. Veronica Raney, Psychiatrist, Medical Director at UAMS Child Study Center discussed guidelines for the clearly defined treatment plan established by the Center of Excellence and Act 1054 of 2021.

Representative Warren made a motion to adopt Guidelines for Accessing PANS/PANDAS Treatment in Arkansas [Handout 1], Representative Cloud seconded the motion and it carried.

#### **Update on Clinic Data at UAMS [Presentation]**

Sandra Bennett, CPAE Nurse, UAMS, presented information regarding the CPAE Clinic.

#### **Other Business**

Senator Hammer asked Cathy Puckett to consider organizing an advocacy group to work with all the entities to ensure that education promotional materials are distributed to keep awareness up.

The meeting adjourned at 12:00 p.m.