

Arkansas PANS/PANDAS Advisory Council Report to Public Health, Welfare and Labor –

House & Senate Committees

November 7, 2022

Organization and Legislation:

- Organized under the direction of the University of Arkansas for Medical Sciences (UAMS) and the Arkansas Children’s Hospital (ACH).
- Act 878 of 2019 created the Arkansas PANS/PANDAS Advisory Council.
- Act 430 of 2021 created the Arkansas PANS/PANDAS Advisory Council after it was sunset in December 2020.
- Act 637 of 2021 authorized off-label use of drug treatments to treat Medicaid beneficiaries with PANS/PANDAS.
- Act 1054 of 2021 authorized off-label use of drug treatments to treat patients diagnosed with PANS/PANDAS.

Affiliation:

- Childhood Post-Infectious Auto-Immune Encephalopathy (CPAE) Clinic at Arkansas Children’s Hospital (ACH) – Dr. Veerapandiyan (neurologist) & Dr. Raney (psychiatrist)
- UAMS Center of Excellence
- PACE Foundation (Paul and Patricia Ryan)
- The Arkansas PANS/PANDAS Advisory Council is networked with the PACE Foundation and consortium consisting of the University of Arizona, UCLA, Stanford, Wisconsin, and Massachusetts General Hospital.

Outcomes:

- The UAMS Center of Excellence hired a full time nurse for the CPAE clinic to focus on patient care. The clinic scheduling changed from twice a month to a regularly scheduled weekly clinic.
- A Collaborative Physician Model was developed similar to Arizona’s through Grand Rounds with the state’s network of physicians.
- UAMS will work with Crisis Intervention Centers statewide. UAMS distributed a brochure to both the Arkansas chapters of American Academy of Pediatrics and Arkansas Academy of Family Physicians.
- The Advisory Council has continued to monitor updates on the IVIG treatments currently in phase three of the trial. The trial has been conducted in universities around the country and has expanded to Europe. The ongoing trial has served as an opportunity for awareness and inclusion.
- The Advisory Council adopted proposed Guidelines for Accessing PANS/PANDAS Treatment in Arkansas to serve as best practices for treatment.
- Rule 127 promulgated by the Arkansas Insurance Department as required by Act 1054 of 2021, authorizes off-label use of drug treatments for PANS. This rule goes into effect January 1, 2022.

- The Department of Human Services promulgated a rule to update the Hospital, Physician and Nurse Practitioner Provider Manuals and State Plan Amendment to add PANS/PANDAS Treatment. The rule became effective June 1, 2022.

Education:

- UAMS has developed and continued to update pediatric and adult informational flyers. Web-based material has been shared from the University of Arizona to the University of Arkansas website for their CPAE Clinic and the Arkansas Department of Health website.
- The Advisory Council has promoted the organization of advocacy groups for members to work with all of the entities involved to ensure educational materials are distributed and to continue awareness.