

**MINUTES
ARKANSAS PANS PANDAS ADVISORY COUNCIL
MAC Room B
Little Rock, Arkansas
Thursday, January 2, 2020
1:00 PM**

The Arkansas PANS PANDAS Advisory Council held its initial meeting at 1:00 p.m. Thursday, January 2, 2020, in the Multi-Agency Complex (MAC), Room B, in Little Rock, Arkansas.

Advisory Council members present: Senator Kim Hammer, Representative Joe Cloud, Chantel Allbritton, Natalie Bradford, Pasley Butler, Ashley Collins, Kelea Duke, Cathy Puckett, Deborah Rice, Sue Tedford, John Vinson, J. Gary Wheeler, M.D., Matt Brumley.

Also attending: Representative Keith Slape.

Senator Hammer called the meeting to order, and asked for official recognition of the advisory council, and for the open position of a medical professional to be named by the council.

**APPOINTMENT OF PANS PANDAS ADVISORY COUNCIL MEMBER AND ACCEPTANCE OF CHAIR RECOMMENDATION FROM THE INTERDISCIPLINARY PANEL
[PUBLIC ROSTER]**

Senator Hammer stated the Interdisciplinary Panel, organized under the direction of the University of Arkansas for Medical Sciences (UAMS) and the Arkansas Children's Hospital (ACH), will make a recommendation for the advisory council chairmen. He recognized Maurice Rigsby, UAMS Vice Chancellor of Institutional Relations, to present the recommendation.

Mr. Rigsby noted on behalf of Dr. Rick Smith, the Interdisciplinary Panel recommends Senator Kim Hammer and Representative Les Warren to serve as co-chairs of the advisory council and Senator Irvin and Representative Cloud to serve as vice chairs.

Representative Joe Cloud made a motion to accept appointment of council members and acceptance of recommended Chairs and Vice Chairs from the Interdisciplinary Panel, and with a second by Mr. John Vinson, the motion carried.

Mr. Rigsby noted Dr. Smith is working to schedule an open house at the ACH clinic and to hopefully have the Ryans (from the Arizona-based PACE Foundation) present at that time also. The clinic is seeing patients, but there has not been a formal opening yet (possibly late February or early March).
[HANDOUT1]

INTRODUCTIONS

Senator Hammer had each member and Bureau of Legislative Research (BLR) staff introduce themselves.

Senator Hammer noted the open medical professional position on the council will work in conjunction with the Interdisciplinary Panel. While this council and the Interdisciplinary Panel may attend each other's meetings, there is expected to be a conduit between the two to ensure working in unison and not be cross purposed with each other. He recommended Matt Brumley for the PANS PANDAS Advisory Council position.

Mr. Matt Brumley, Director of Saline Health Foundation, noted his medical professional background is licensed paramedic and Director of Emergency Ambulance Service and Interim in the Emergency Department at Saline Memorial Hospital. He first encountered PANS PANDAS three years ago in a patient that was diagnosed with symptoms caused by brain inflammation. Later the diagnosis was changed to post infectious auto immune encephalitis and before the patient's next scheduled appointment, he took his own life. Soon after this, Mr. Brumley invited Senator Hammer to hear talks about the condition.

Ms. Tedford made a motion to appoint Matt Brumley to the PANS PANDAS Advisory Council, and Ms. Bradford seconded the motion. The motion carried.

CONSIDERATION TO ADOPT PANS PANDAS ADVISORY COUNCIL RULES OF PROCEDURE [EXHIBIT D]

Mr. Brumley made a motion to adopt PANS PANDAS Advisory Council Rules of Procedure as presented. Ms. Tedford seconded the motion, and the motion carried.

DISCUSSION OF ACT 878 OF 2019 CREATING THE PANS PANDAS ADVISORY COUNCIL [EXHIBIT E]

Ms. Alix Stephens, Legislative Attorney, BLR, explained parts of the act and Senator Hammer provided additional information. [HANDOUT E]

PANS PANDAS CLINIC AT ARKANSAS CHILDREN'S HOSPITAL

Dr. Aravindhan Veerapandiyan (Dr. Panda), Child Neurologist with specialized training in neuromuscular medicine, Medical Director of the Headache Clinic at ACH, noted he will be co-directing the Childhood Post-Infectious Auto-Immune Encephalopathy (CPAE) Clinic at ACH. He noted the disease is not being brought up in a doctor's training, so there is a lack of awareness among pediatricians. The condition's preferred reference is CPAE, meaning inflammation in the brain following some type of infection. The Arkansas CPAE Clinic is beginning to receive referrals and will officially open in a few weeks.

He noted he was selected because of his experience with multi-disciplinary clinics -- those with multiple providers in one clinic, for example psychiatrists, psychologists, and others, who can all see the patient during their visit.

He and Dr. Raney learned about the PACE Foundation, which Paul and Patricia Ryan founded because their grandson was affected with this and initially was not treated properly. Their goal is to streamline this process to have a standard of care, standard of practice, and a protocol criteria to diagnose and treat the disease. Currently, there are four centers in the U.S., and Arkansas will be the fifth. The Ryan's goals include creating awareness among pediatricians, other doctors, and communities across the country.

Dr. Veerapandiyan noted the Interdisciplinary Panel consists of Dr. Smith, himself as the neurologist, Dr. Raney as the psychiatrist, and there will also be a psychologist.

Dr. Veronica Raney, Psychiatrist, Medical Director at UAMS Child Study Center at ACH, noted she has been working with Dr. Veerapandiyan to get the CPAE Clinic started. Immune diseases, when

first discovered, are often written off and discounted as imaginary because it is hard to come up with good tests, and a system of how to diagnose the disease, e.g. MS.

From Dr. Raney's psychiatric perspective, in terms of understanding the medical issues, there is evidence of a physical cause. This disease has a start that is different and does not fit the classic history of typical psychiatric issues when looking at the disease progression. She thinks it is important to raise awareness of the disease and to ensure a standardized approach to it. She noted education is key, because of the stigma of anything in the mental illness category.

Dr. Wheeler added he serves as President of the American Academy of Pediatrics Chapter in Arkansas. The focus of their work 20 years ago was infectious diseases, but now the majority of their focus is dealing with behavioral issues for which they feel unprepared. He stated having a network of academic facilities trying to standardize this disease is going to be a tremendous advance. He asked who had jurisdiction to alter the way any disease is paid for by insurance companies in Arkansas.

Senator Hammer said this legislation was written with the intent that a billing ICD-10 code be established under which this disease can be billed.

Ms. Allbritton noted if this were to be made a mandated benefit, insurance companies would have to pay. Discussions within the Arkansas Insurance Department's Legal Division would need to take place.

Dr. Veerapandiyan thinks the insurance coverage is mainly focusing on the intravenous immunoglobulin (IVIG) part of the code because the rest of the treatment is standard, simply using antibiotics or anti-inflammatory medicines.

Senator Hammer and Representative Warren agreed to break the advisory council into subcommittees to take on required issues and bring recommendations to the full council.

Senator Hammer stated the intent is to have monthly meetings with two subcommittees of this council and the chairs and vice chairs helping with the focus outlined under Duties of the Rules of Procedure.

Representative Cloud made a motion to create two subcommittees from the Arkansas PANS PANDAS Advisory Council, one focusing on items a-c under Duties of the Rules of Procedure, the second will focus on items d-e. Ms. Bradford seconded the motion, and the motion carried.

Senator Hammer asked each member to respond to Ms. Stapleton regarding their preferred subcommittee.

OTHER BUSINESS

Senator Hammer noted he and Senator Irvin agreed on a future joint meeting with the House and Senate Public Health Committees and this advisory council. He also suggested an advisory council meeting, with speakers Mr. and Mrs. Ryan, founders of PACE, should be set one hour before the joint meeting with Public Health.

ADJOURNMENT

With no further business, the meeting adjourned at 2:39 p.m.